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**An investigation into the factors associated
with psychological adjustment in men and women
who have undergone surgery for colorectal cancer**

Kate Baylis

July 1999

**A thesis submitted in partial fulfilment of the requirements of the Open University/
British Psychological Society Doctorate in Clinical Psychology**

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APPENDICES HAVE NOT BEEN SCANNED ON INSTRUCTION FROM THE UNIVERSITY

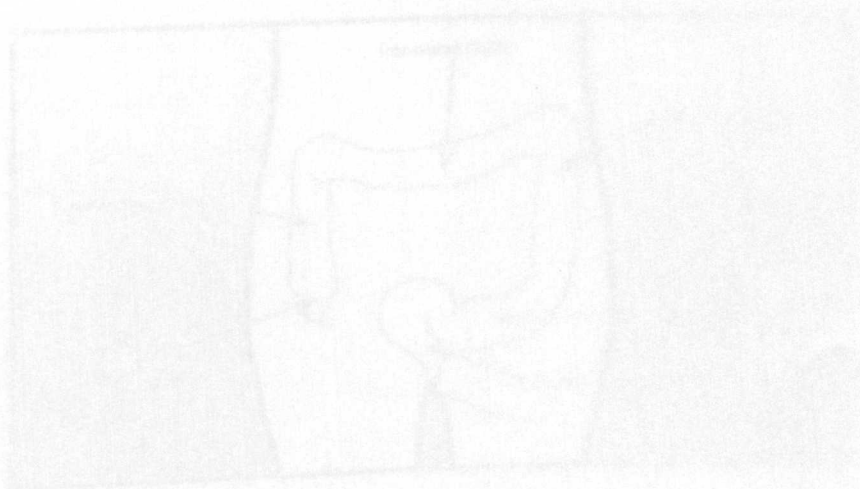


Figure 1. The hand holding the pen.

ABSTRACT

Colorectal cancer is a major health problem for both men and women today. It is also one of several site-specific cancers that patients are likely to survive beyond five years of diagnosis. The majority of patients show good psychological adjustment following the diagnosis and treatment of colorectal cancer. However, the literature suggests that approximately one quarter of patients continue to have clinically significant psychological symptoms at least one year after diagnosis. This study aimed to investigate psychological adjustment in 33 colorectal cancer patients (1-2 years post-surgery); and to explore a series of demographic, disease and treatment, psychological and social factors that may be associated with psychological adjustment. A secondary aim of the study was to explore colorectal cancer patients' perceptions of, and satisfaction with, care during diagnosis and treatment. Results showed lower levels of psychological distress (anxiety and depression) than those reported in previous studies with under 10 per cent of clinically significant cases. Levels of psychological distress were associated with age, disease severity and the presence of other concurrent physical health problems. Coping style was found to relate significantly with psychological adjustment. Taking the methodological limitations of this study into consideration, the results are interpreted in the context of the empirical and theoretical literature. Clinical and research implications are also discussed. A larger scale, longitudinal evaluation of the issues is clearly needed.

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1. INTRODUCTION

In the first section of the introduction a brief overview of colorectal cancer will be presented, including the characteristics of the disease and some of the issues associated with diagnosis and treatment. The increase in long-term survival rates of cancer patients, particularly in patients with colorectal cancer, will then be considered.

The psychological impact of being diagnosed with and treated for cancer will then be discussed. Although there is a large research literature on psychological outcomes after certain cancers (e.g. breast cancer), there is limited data on other site-specific cancers. The growing body of research that focuses specifically upon psychological outcomes in colorectal cancer will then be summarised. The term 'psychological adjustment' will be used to refer to adaptation to disease without continued elevations of psychological distress, particularly anxiety or depression.

The relationship between physical health, psychological outcome and physical outcome in colorectal cancer will then be put into a theoretical context. The biopsychosocial model of health and illness (Engel, 1977, 1980) will be used as a broad framework. The evidence for a range of factors considered to put cancer patients at risk of psychological distress will then be reviewed. These include demographic variables, disease and treatment variables, a range of psychological mediating variables (e.g. coping styles, self-efficacy) and environmental factors (e.g. support systems). Additional specific theories will be drawn upon in relation to some of these factors, including theories of lifespan development, coping and self-efficacy.

Finally, an outline of the research questions and hypotheses will follow the rationale for the current study.

1.1 Overview of colorectal cancer

1.1.1 Characteristics of colorectal cancer

Colorectal cancer refers to cancer in any part of the large bowel; about two-thirds of tumours occur in the colon and the remainder occur in the rectum and rectosigmoid (see Fig. 1). It is the second most common form of cancer and the sixth most common cause of death overall, causing over 19 000 deaths each year in the United Kingdom (Office of Population Census and Surveys, 1995; Scottish Health Statistics, 1991). Its incidence is 48 per 100 000 per year, rising sharply with age. The median age at diagnosis is 70 and it is rare in people under 50 years old. Colon cancer occurs at roughly equal rates in both men and women, but rectal cancer is more common in men. Around 75 per cent of patients have neither a positive family history nor any condition known to predispose them to developing colorectal cancer (e.g. chronic ulcerative colitis) (Winawer, Fletcher, Miller *et al.*, 1997).

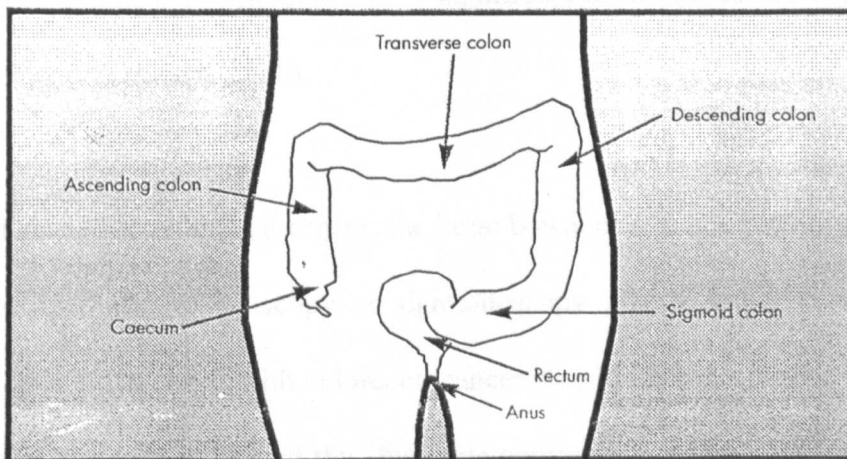


Figure 1. The large intestine

The disease is curable when not too far advanced. The effectiveness of treatment and prospects for survival depend crucially on the degree to which the cancer has spread at diagnosis, usually described in terms of a Dukes' stage classification (see Table 1). Symptoms may not become apparent until the disease has advanced, and widespread screening is not yet common place.

Table 1. Colorectal cancer staging, stage distribution and five-year survival rates

Dukes' stage	Definition	Approx. frequency at diagnosis	5-year survival
A	Cancer localised within the bowel wall	11%	83%
B	Cancer which penetrates the bowel wall	35%	64%
C	Cancer spread to lymph nodes	26%	38%
D	Cancer with distant metastases (e.g. liver)	29%	3%

The most common presenting symptoms include a change in bowel habit, rectal bleeding, anaemia, weight loss, nausea and abdominal pain. As these symptoms can occur relatively commonly with a variety of causes, confusion with benign bowel conditions (e.g. haemorrhoids) or with age-related changes is not uncommon. In addition, patients often delay seeking help, by approximately 3 months, usually because they do not think that the symptoms signify significant illness (Crosland & Jones, 1995; Prohaska, Funch & Blesch, 1990).

In cases of suspected colorectal cancer, the large bowel can be completely examined by one of two methods: colonoscopy or sigmoidoscopy plus a double-contrast barium enema. Patients diagnosed with colorectal cancer should undergo further investigation to establish disease severity, and thus facilitate appropriate treatment, using a range of imaging techniques (e.g. ultrasound, CT scan). These initial investigations can be

uncomfortable, painful and embarrassing for the patient (Allen, 1997).

1.1.2 Treatments for colorectal cancer

The treatment of colorectal cancer has changed considerably in recent years. New surgical techniques have substantially reduced the need for permanent stomas (i.e. passage constructed through the abdominal wall) and standard treatment may include radiation, chemotherapy or both (Barsevick, Pasacreta & Orsi, 1995). Surgery to remove the tumour is the principal first line of treatment for approximately 80 per cent of patients. Long-term survival is only likely when the tumour is completely removed. When the tumour is very low in the rectum, there may be no alternative to abdomino-perineal resection necessitating stoma formation.

However, recent guidelines suggest that surgeons should aim, whenever possible, to use operations which conserve the anal sphincter and avoid the need for a stoma (NHS Centre for Reviews and Dissemination, 1997). As a result the use of advanced sphincter saving surgical procedures such as ultra low anastomosis (i.e. resection up to 2.5 cm from the anal verge) are increasing (Sprangers, Taal, Aaronson & te Velde, 1995). However, all these surgical procedures can adversely affect several aspects of well-being; for example, bowel function may be problematic regardless of whether stoma-formation is necessary (Allen, 1997).

Chemotherapy and pre- and post-operative radiotherapy may be included as adjuvant treatment for colorectal cancer. Radiotherapy in particular can be highly effective in reducing symptoms due to locally advanced rectal cancer. Chemotherapy can be

beneficial in more advanced cancers, although in cases of less disease severity (e.g. Dukes stage B), it is not yet clear whether the benefits outweigh the adverse effects upon quality of life (NHS Centre for Reviews and Dissemination, 1997).

Patients who have had surgery are often followed up, as frequently as every 3 months, to detect recurrences of the cancer that may also be treatable. However, most recurrences are discovered as a result of symptoms reported by patients (Wessex Colorectal Cancer Audit, 1996).

1.2 Surviving cancer

As a result of treatments that are more effective and earlier detection, the long-term survival rate of cancer patients in general has risen dramatically during the past few decades. Long-term survival may be defined as survival beyond 5 years of diagnosis, since most recurrences occur within 5 years of diagnosis. So for many, cancer will be a survivable disease and most individuals will cope and resume their life patterns if they remain disease free. Epidemiological data indicate that, for women, cancer survivors come primarily from gynaecological, breast and colorectal cancer and, for men, primarily from colorectal, prostate and bladder cancer (Anderson, 1994). Thus, colorectal cancer is one of several survivable site-specific cancer groups, and it is one that affects both men and women.

One approach to attempt to reduce cancer incidence and mortality is to focus research initiatives on the site-specific cancers which patients are most likely to survive (Anderson, 1994). For example, a series of NHS Executive guidance documents on site

specific cancers have been commissioned in order to improve the standard of care for cancer patients. The first, which focused on breast cancer, was followed by guidance focusing on colorectal cancer (Cancer Guidance Sub-Group of the Clinical Outcomes Group, 1997).

As a result of increased long-term survival rates, healthcare professionals are faced with a new challenge: helping people to live with cancer or live with having had cancer (Scott & Eisendrath, 1986). Although there is a large data base on quality of life outcomes after breast cancer, data on other identified cancer survivor groups, including colorectal cancer, are limited (Anderson, 1994). The psychological impact of cancer diagnosis and treatment will be considered next.

1.3 The psychological impact of cancer

1.3.1 Cancer in general

For cancer sufferers across the board, the research suggests that there is a generally positive prognosis in terms of psychological distress (Anderson, 1994). However, there are likely to be “islands of life disruption” such as during diagnosis, treatment and the end stages of cancer. Holland (1989) reported that almost half of hospitalised patients with cancer meet criteria for formal psychiatric disorders. However, as the patient learns what to expect with regard to treatment plan, psychological distress often diminishes.

The most common responses to cancer diagnosis and treatment are adjustment disorders, with anxiety and depression being the most prevalent. However, prevalence

figures vary greatly with reported rates of anxiety and depression ranging between 5-50 per cent (Massie, 1990). The reasons for such discrepancies include the fact that, first, psychological assessment measures have sometimes included somatic symptoms (e.g. poor appetite, loss of energy) that may be disease symptoms or treatment related effects. Second, assessments have been performed at varying times after diagnosis, thus failing to take normal adaptation into account. Third, many studies have examined cancer samples that are heterogeneous with respect to cancer diagnosis. Physiological processes, problems and treatment are distinct among cancers and have widely varying outcomes; psychosocial processes are different depending both on the diagnosis and type of treatment.

Despite these variations, one consistent finding is that the level of distress declines substantially within one year of treatment (Glanz and Lerman, 1992). However, approximately 20 per cent of cancer survivors will continue to experience significant adjustment difficulties. Even for many long-term survivors (i.e. 5 years or more), the negative effects of cancer and/ or treatment upon daily life, particularly in terms of psychological functioning, may continue well beyond the completion of therapy (Cook Gotay & Muraoka, 1998). Compas & Harding (1998) suggest that the stress entailed in treatment, recovery and long-term living with uncertainty may be more adverse than the original trauma of the cancer diagnosis.

1.3.2 Colorectal cancer

A limited but growing body of research has focused upon psychological adjustment following diagnosis and treatment of colorectal cancer. For patients with colorectal

cancer, the prognosis is considerably better than for many other site-specific cancers. Nevertheless, bowel surgery in general, and stoma surgery in particular, is an intrusive operation with a great impact on daily life. The patient must cope with a severe operation, the loss of an important body function, a distortion of body image, and a change in physical functioning and personal hygiene/ care.

The most common psychological problem that is reported in colorectal cancer patients following treatment is depression. Sprangers and colleagues (Sprangers, te Velde, Aaronson & Taal, 1993) reviewed 22 studies that assessed quality of life, including psychological functioning, in colorectal cancer patients between 1-10 years post-surgery. They reported that approximately one quarter of patients, both those with and without a stoma, had clinically significant psychological symptoms; with rates of depression varying between 14-50 per cent and anxiety varying around 25 per cent. However, the point at which psychological distress is assessed may be a significant factor. For example, Whynes & Neilson (1997) reported that pre-treatment levels of psychological distress in colorectal cancer patients had dissipated by 3 months post-surgery, and may have resulted from anticipation of treatment.

In a follow-up paper, Sprangers and colleagues (Sprangers, Taal, Aaronson, & te Velde, 1995) suggested that, contrary to initial opinion, surgical procedures preserving body parts such as the sphincter do not automatically convey a good quality of life with good psychological adjustment. The authors conclude that additional well-designed studies are needed to explore the effects of surgical procedures on the quality of life of colorectal patients, particularly in the domain of psychological functioning. Barsevick

and colleagues (Barsevick, Pasacrete & Orsi, 1995) also conclude that further research is needed in the context of today's more intensive treatment approaches which employ advanced surgical techniques (e.g. ultra low anastomosis) and radiation, chemotherapy or both as standard.

Given that the majority of colorectal patients do not experience adverse psychological effects, Sprangers and colleagues also suggest that efforts should be made to identify those subgroups that are most vulnerable to the adverse psychological sequelae of the disease and treatment.

1.4 Theoretical framework

The importance of exploring psychological adjustment in cancer patients is underlined by the finding in cancer samples that psychological responses to illness, if negative, can result in unfavourable physical health outcomes (e.g. functional dependency and morbidity) (e.g. Barsevick *et al.*, 1995). This is an area that has received great interest both in the theoretical and empirical literature.

1.4.1 The biopsychosocial model

A variety of theories have been developed to explain the relationship between physical health, psychological outcome and physical outcome; and multiple phases of a disease process (e.g. cancer) have been considered including onset, exacerbation and recovery. Engel (1977, 1980) provides a multifactorial biopsychosocial model of health and illness. The basic distinguishing feature of this model is that psychological and social factors can both influence and be influenced by pathophysiological or biological

processes. Engel (1980) applied the concept of “systems” (von Bertalanffy, 1968) to the model by proposing that it is the interplay of three major systems that affects health and illness (see Fig. 2). The model also places smaller, simpler systems within larger, more complex ones. ‘Biological systems’ include genetics, viruses and physiological functioning at all levels (e.g. organs, tissues and cells). ‘Psychological systems’ include behaviour, cognition, emotion and coping style. ‘Social systems’ range from aspects of close social relationships (e.g. family) to aspects of the wider social environment (e.g. employment, socioeconomic status and culture). The systems are dynamic and interrelated; thus each system can affect and be affected by any of the other systems.

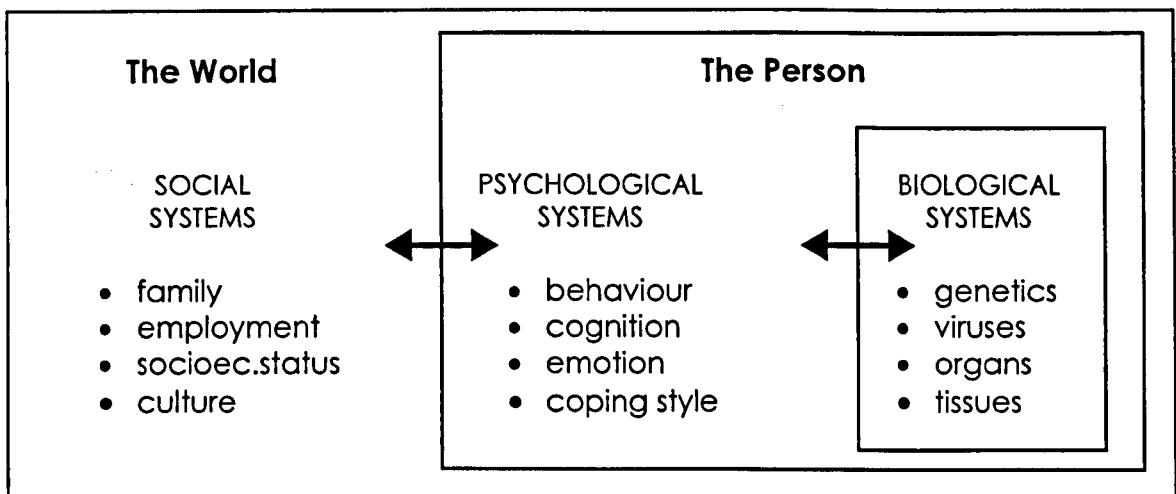


Figure 2. A diagram of the interplay of systems in the biopsychosocial model.

Psychological and social factors are therefore not only considered as possible consequences of an illness, but also as contributing to its’ aetiology and course. Nicassio and Smith (1996) outlined various ways in which psychosocial factors may exert an influence upon physical health outcomes. First, there may be a direct effect (e.g. anxiety may increase muscle tension). Second, there may be an indirect effect

which involves more complex relationships and physiological or behavioural mediational processes (e.g. a patient who uses denial of their illness as a coping strategy may show poor compliance with their treatment regime, and consequently experience worsening of their illness). Third, there may be a moderator effect, whereby the variable alters the relationship between a causal factor and health outcome (e.g. those who receive high or effective social support may be less likely to develop depression in the face of life stress).

1.4.2 Empirical findings

For patients with chronic conditions, the association between psychological factors and physical outcome has been explored in terms of the pathophysiological process itself, the subjective severity of related symptoms (e.g. pain) and the behavioural sequelae of the disease (e.g. impaired social role). Wells and colleagues' (Wells *et al.*, 1989) survey data suggested that the effect of depressive symptoms and chronic medical conditions (e.g. hypertension, diabetes, arthritis) on functioning are additive, resulting in twice the reduction in social, role and physical functioning as either condition alone.

In patients with colorectal cancer, Barsevick *et al.* (1995) reported that having depressive symptoms before or after the operation and having stoma surgery, contributed significantly to the prediction of functional dependency at 3 months post-operatively (i.e. functioning less well in usual roles and activities). In a prospective longitudinal study, Bekkers, van Knippenberg, van Dulmen, van den Bourne & van Berge Henegouwen (1997) found that patients with poor adjustment at 4 months post-

stoma surgery were at significantly higher risk of death or terminal status at the 1 and 4 year follow-ups. This was especially so for those with colorectal cancer as opposed to benign bowel conditions.

In summary, even though the biopsychosocial model promotes ‘causal’ influences between systems, in most instances the relevant empirical research is limited. Nevertheless, the biopsychosocial model does provide a framework for investigating psychological adjustment in patients following the diagnosis and treatment of cancer. It also provides a conceptual framework within which to explore the factors that may mediate the relationship between the diagnosis and treatment of cancer and psychological adjustment.

1.5 Factors influencing psychological adjustment

A number of factors have been linked to psychological adjustment in men and women with cancer. These include demographic variables, disease and treatment variables, a range of psychological mediating variables (e.g. coping styles, self-efficacy, stigma) and environmental factors (e.g. social support). These may be seen as interrelated factors occurring in the biological and psychological systems within the person, and in the social systems within the world. In the review of these variables that follows, additional theoretical approaches will be drawn upon where relevant. Empirical findings from the available studies that focus specifically upon the psychological impact of colorectal cancer will then be summarised. Otherwise, empirical findings regarding the psychological impact of other site-specific cancers will be drawn upon. The review will also consider long-term psychological adjustment (i.e. at least 1 year post-diagnosis and

treatment) as opposed to acute post-surgical adjustment, unless otherwise stated.

1.5.1 Demographic variables

Age

Taking a lifespan perspective, cancer constitutes a major stress that is added to the normal stresses of adaptation to age-appropriate tasks across the life cycle. Cancer in younger adulthood may disrupt developmental tasks such as career development and raising children; there may also be fewer peers who have experienced cancer and who can provide support (Compas and Harding, 1998). During older adulthood (i.e. 46-65 years) many anticipated tasks or approaching (emotional, physical and social) changes are actually realised, making associated disruptions (e.g. cancer) particularly keenly felt. For the ageing adult (66 years and over), cancer may come in the context of multiple personal losses (i.e. physical, financial and social) (Rowland, 1990).

In colorectal cancer, age is an important predictor of psychological distress, in that older patients seem to fare better than younger patients (Forsberg & Bjoervell, 1996; Sprangers *et al.*, 1993).

Gender

The field of general mental health is one where women consistently outnumber men in the presentation and treatment of problems. Ussher (1997) suggests that multifactorial models, which acknowledge biological and psychosocial factors, may be the most appropriate. In colorectal cancer, the psychological functioning of younger, female patients seems to be more impaired than that of older, male patients (Sprangers *et al.*,

1993). Following stoma surgery, MacDonald and Anderson (1984) found that women were more likely to feel the stigma of changed appearance than men. Baider, Perez & De-Nour (1989) also found that, after non-stoma surgery, women reported higher levels of distress and were less well-adjusted psychosocially than were their male counterparts.

Marital status

Early research in cancer suggested that marriage bestowed major health benefits through its' provision of social support (Baider, Kaufman, Peretz, Manor, Ever-Hadini & De-Nour, 1996). However more recently, in light of findings that cancer has an impact upon the whole family, the role of spouses in constituting a "distress" system as opposed to a support system has been considered.

In a sample including male and female colorectal cancer patients who underwent non-stoma surgery (i.e. 62 per cent of sample), Baider *et al.* (1996) reported that spouses were just as distressed as patients; moreover, patient distress contributed significantly to spouse distress and vice versa. In a more recent study, Baider and colleagues (Baider, Walach, Perry & De-Nour, 1998) reported that psychological distress in married couples with both partners diagnosed with cancer was not significantly different than when only one partner had cancer.

Level of education, socioeconomic status and cultural background

Those with less formal education may experience greater distress because they have less experience processing the complex information that confronts them as part of their diagnosis and treatment. Cancer patients from lower socioeconomic groups may also

have fewer resources available to them, placing them at greater risk for psychological distress (Compas and Harding, 1998). Level of education and lower socioeconomic status have been found to be associated with psychological distress in cancer patients (e.g. Stoll, Oppendisano, Epping-Jordan, Compas & Krag, 1997); although this has not been investigated specifically in colorectal cancer patients.

In the wider social context, while cancer imparts negative consequences universally, the meaning of cancer and how families deal with the disease varies greatly as a function of cultural factors. Cook Gotay (1996) describes how the threat of cancer to an individual's independence may be of greater importance in Anglo cultures than in many Asian cultures, where interdependence or "connectedness" is more highly valued. Anglo cultures may also value openness and full disclosure of information, whereas many Asian cultures prefer to "protect" the patient.

Illness co-morbidity, history of psychiatric problems and additional life events

Co-morbidity of chronic illnesses has been found to result in greater decrements in mental health, as well as a decrease in social and role functioning, compared to those with only one chronic condition (Stewart, Greenfield, Hays *et al.*, 1989). In colorectal cancer, some chronic conditions may serve as risk factors and increase the likelihood of co-morbidity (e.g. inflammatory bowel disease). In addition, existing health conditions may limit the cancer treatments that can be offered and their efficacy.

A history of psychiatric disorder, particularly depression, may increase the risk of psychological distress after a cancer diagnosis (Plumb & Holland, 1981). People with

stressful life events of a severe kind in addition to cancer (e.g. bereavement) may also be at risk of psychological distress in response to cancer (Division of Clinical Psychology, 1997). The association between concurrent physical health problems, a history of psychiatric problems and additional concurrent life events with psychological adjustment in colorectal cancer patients has yet to be fully investigated.

1.5.2 Disease and treatment variables

Family history of colorectal cancer

Beck's cognitive theory of depression (Beck, Rush, Shaw & Emery, 1979) proposes that negative life events (e.g. diagnosis of cancer) activate latent schemas in memory that represent an accumulation of relevant past experience. Consistent with this theory, depression among heterogeneous cancer patients has been found to be associated with a high frequency of intrusions of specific autobiographical memories that revolve around themes of illness and death and that are often cancer-related (Brewin, Watson, McCarthy, Hyman, & Dayson, 1998). These memories, some concerning the patients' own illness but many involving experiences with family and friends, may be a persistent source of information that feeds into and maintains maladaptive coping and negative cognitions about the future. Patients who come from a family with a high genetic risk of colorectal cancer and those who are part of a "cancer family" may therefore be at greater risk of psychological distress (Holland, 1990). The prospect of being at high genetic risk and experiencing the death of family members by the same disease may add to the fear and depression.

Disease severity

The pathological stage of the disease, which is by far the most important predictor of survival outcome, may also predict psychological distress (Thomas, Turner & Madden, 1988). Patients who have been informed that they have a poor prognosis with no chance of a cure may understandably experience higher levels of psychological distress than those who are likely to be 'cured'. Prevalence estimates of psychological distress in palliative cancer care (61-79 per cent) are higher than those found in the general cancer population (18-34 per cent) (Vachon, 1993).

Nordin and Glimelius (1997) reported on a sample of recently diagnosed (i.e. within 4 weeks) gastrointestinal cancer patients (i.e. colon, rectal, gastric and biliary/ pancreatic cancer). They found significantly higher levels of both anxiety and depression in 'non-cured' patients than in 'cured' patients, although neither mean anxiety or mean depression scores reached clinical 'case' levels. Clearly, the relationship between disease severity and distress is also dependent upon how clearly information regarding prognosis is given and how the patient perceives it. There are no specific studies focusing upon longer-term psychological adjustment and disease severity in colorectal cancer patients.

Type of surgery (stoma vs. resection)

A long-standing debate in cancer surgery has been the relative influence of the knowledge of the diagnosis (e.g. breast cancer) compared to the self-image distorting aspects of the surgery itself (e.g. mastectomy) (Thomas, Turner & Madden, 1988). The diagnosis of colorectal cancer and stoma surgery is also an example of this debate.

The literature has explored psychological adjustment to stoma surgery in patients with colorectal cancer and benign inflammatory bowel disease (e.g. Crohn's disease). Prospective studies (e.g. Thomas, Turner & Jehu, 1984; 1987) and retrospective studies (reviewed by Bekkers, van Knippenberg, van Dulmen *et al.*, 1995) have found similar levels of psychological distress in benign and malignant conditions (i.e. around 25 per cent). The results also suggested that technical improvements in stoma care over the previous decade had not resulted in a decline in psychosocial problems after surgery.

The literature has also explored psychological adjustment to stoma surgery by including a non-stoma bowel resection comparison group. In their longitudinal prospective investigation, Bekkers *et al.* (1997) found no differences between stoma and non-stoma patients, with benign and malignant conditions, at 1 and 4 year follow-ups. However, in their comprehensive review focusing on colorectal cancer, Sprangers *et al.* (1993) reported that patients with stomas may be at a slightly greater risk of depression than those not requiring stomas.

Adjuvant therapy

Cancer patients who must undergo radiotherapies and chemotherapies may experience particular difficulties; indeed, some patients may refuse recommended adjuvant therapies because of the noxious side-effects (Division of Clinical Psychology, 1997). Chemotherapy, which may entail months of treatment and cause recurrent nausea, hair loss and fatigue, has been found to produce substantial psychological distress in general cancer samples (e.g. Maguire, Tait, Brooke & Selwood, 1980). In comparison, radiotherapy, which also causes fatigue and listlessness, has not been found to cause as

much psychological distress (Wallace, Priestman, Dunn & Priestman, 1993). There are no specific studies investigating the psychological impact of adjuvant therapy in colorectal cancer.

1.5.3 Psychological mediating variables

A range of psychological factors have been hypothesised to mediate the relationship between the stress of cancer diagnosis and treatment and psychological adjustment. An ever-growing body of research is investigating these factors in cancer populations.

Coping

Lazarus & Folkman (1984) defined coping as constantly changing cognitive and behavioural efforts to manage specific external and/ or internal demands that are appraised as taxing or exceeding the resources of the person (e.g. cancer and treatment). Classifications of coping often refer to the specific strategies or general styles people adopt, regardless of their efficacy. A relatively consistent finding is that active problem focused strategies (i.e. focusing on the demands of the stressful situation) are associated with better adjustment to chronic disease than avoidant emotion focused strategies (i.e. focusing on the associated negative emotions) (Maes, Leventhal & de Ridder, 1996).

In terms of coping with cancer, Watson and colleagues suggested five dimensions (i.e. coping styles) that may relate to psychosocial well-being in cancer patients (Watson, Greer, Young, Inayat, Burgess & Robertson, 1988). Of these coping styles 'anxious

preoccupation'¹, 'fatalistic'² and 'hopelessness/ helplessness'³ have been found to relate positively to anxiety and depression, while 'fighting spirit'⁴ has an inverse relationship. No specific relationship is suggested for the fifth dimension 'avoidance'⁵.

In coping after stoma surgery, Thomas *et al.* (1988) found that, in patients with colorectal cancer and benign conditions, psychological distress was lower in those who adopted a 'fighting spirit' coping style, and higher in those with a 'helplessness/ hopelessness' style. Furthermore, they found that difficulty coping with the stoma (i.e. 'helplessness/ hopelessness') was a greater determinant of psychiatric distress than coping with the illness itself.

Nordin & Glimelius (1997) found that patients newly diagnosed (i.e. 4 weeks post-diagnosis) with colorectal cancer, most of whom were potentially 'cured', had a more confrontational attitude towards their diagnosis than gastric, biliary and pancreatic cancers patients. They reported more 'fighting spirit', and less 'hopelessness/ helplessness' and 'anxious preoccupation'⁶.

Self-efficacy

Self-efficacy refers to an individual's expectation that he or she can perform a particular task or behaviour. According to Bandura (1991), those with high-efficacy expectations

¹ reacts to diagnosis with marked persistent anxiety and accompanying depression.

² accepts diagnosis; does not seek further information.

³ engulfed by knowledge of the illness; difficulty thinking of anything else; pessimistic attitude; daily life disrupted by fears concerning cancer and possible death.

⁴ characterised by acceptance of the diagnosis; use of the word 'cancer'; determination to fight the illness; tries to get as much information as possible about it; adopts an optimistic attitude; may see illness as a challenge.

⁵ does not really believe diagnosis.

⁶ The mean scores were as follows: 'fighting spirit' (50.1), 'helplessness/ hopelessness' (7.8) and 'anxious preoccupation' (15.4).

feel that they are able to call on reserves to meet the challenges involved with coping with stressors (e.g. cancer). In contrast, those low in efficacy may feel overwhelmed by the demands of their situation. Applications of the theory in oncology suggest that increased self-efficacy is associated with adjustment to the cancer diagnosis, increased adherence to treatment, increased self-care behaviours, and decreased physical and psychological symptoms (reviewed by Lev, 1997).

Significant correlations have been found between self-efficacy and psychological adjustment in cancer patients. This has been found using self-efficacy measures closely related to treatment goals (Bekkers, van Knippenberg, van den Bourne *et al.*, 1996; Cunningham, Lockwood and Cunningham, 1991) and taking patient expectancies about control over cancer-related symptoms into account (Beckham, Burker, Lytle, Feldman & Costkis, 1997); and using measures developed specifically for coping with cancer (Cancer Behaviour Inventory: Merluzzi & Martinez Sanchez, 1997).

Although the concept of self-efficacy was originally developed for investigating very specific behaviours, there has been growing interest in measures of generalised self-efficacy (e.g. Schwarzer, 1992). These reflect the strength of general beliefs in one's ability to respond to and control new environmental demands and challenges. Such measures are therefore quite similar to dispositional measures (e.g. optimism). The role of generalised self-efficacy in mediating the psychological impact of colorectal cancer upon psychological adjustment has yet to be investigated.

Stigma

Stigma may be defined as damaging social influences perceived by the patient (McDonald and Anderson, 1984). Colorectal cancer patients may face the double stigma of cancer and stoma surgery. Both stoma and non-stoma surgery may be associated with practical problems with odour, noise and leakage, thus violating strong social taboos about defecation.

McDonald and Anderson (1984) reported that 50 per cent of patients treated for rectal cancer, with stoma and non-stoma surgery, perceived some degree of stigmatisation. Over a third of patients agreed with an item about feeling 'worse about themselves' and a quarter agreed that their 'married life had changed as a result of their bowel condition'. The most frequently endorsed problems were 'self-consciousness' and 'decreased attractiveness'. They found that younger patients, especially young women, and patients with a stoma were more likely to feel stigmatised. Feelings of stigma were also found to correlate with poorer physical health and greater emotional distress.

1.5.4 Social support

In terms of the social functioning of colorectal cancer patients, Sprangers and colleagues' review (Sprangers *et al.*, 1993) suggested that deterioration in the quality of relationship with family and friends may be common, although the bond with the partner seems to suffer less. Social activities may also be restricted, particularly those outside the house.

Social relationships

A wide research literature has indicated the importance of social support in well-being, and also suggests that it has a moderating role in stress/ immunity relationships and health outcomes (e.g. Cohen & Wills, 1985). Although elaborate methods of assessing social support have been employed, simple methods that document a proxy variable (e.g. marital status, domestic status) have also been used. The provision of social support may be defined as emotional (i.e. communication of caring), informational (i.e. provision of information used to guide or advise) or instrumental (i.e. provision of material goods). Helgeson & Cohn's (1996) review suggested that emotional support is most desired by cancer patients and is most strongly related to psychological adjustment, regardless of which network member is providing the support. Ell, Nishimoto, Mediansky, Mantell & Hamovitch's (1992) prospective study included colorectal cancer patients 6-9 months after diagnosis. They found that the perceived adequacy of social support was strongly related to psychological adjustment.

The relationship between social support and psychological adjustment in cancer patients may also be dependent upon other variables (e.g. level of functional disability imposed by the disease). In a cross-sectional study of breast and colorectal cancer patients, Dunkel-Schetter (1984) found a positive association between social support and positive affect in those with a good prognosis, but not in those with a poor prognosis. The role of negative responses in social support has also been explored (e.g. physical avoidance of the patient, avoidance of open communication with the patient, engaging in forced cheerfulness). Manne, Taylor, Dougherty & Kemeny (1997) found that the negative aspects of close relationships were more strongly associated with psychological distress

than the positive aspects.

Patient-provider communication

The research into social support has also considered patient-provider communication, particularly the way in which a patient is given their diagnosis of cancer. In a retrospective study, Butow, Kazemi, Beeney, Griffin, Dunn & Tattersall (1996) reported that patients who were satisfied with the method of communicating their cancer diagnosis (measured several years after diagnosis) reported less emotional distress (at 3 months post-diagnosis) than those who stated they would have preferred a different method of communication (e.g. more emotional support as they underwent diagnosis).

1.5.5 Summary

The literature suggests that, following the diagnosis and treatment of colorectal cancer, approximately one quarter of patients have clinically significant psychological symptoms. The evidence from studies of cancer in general, and from studies which focus specifically on colorectal cancer when available, suggest that a range of biological, psychological and social factors increase the risk of psychological distress following diagnosis and treatment. The evidence for demographic factors includes younger age, female gender, single marital/ domestic status, fewer years in education, lower socioeconomic status, illness co-morbidity, history of psychiatric problems and concurrent stressful life events in addition to cancer. The evidence for disease and treatment variables includes a family history of colorectal cancer, advanced disease severity, stoma surgery and adjuvant therapy. The evidence for psychological and social mediating variables includes low 'fighting spirit', high 'anxious preoccupation',

high 'helplessness/ hopelessness' and high 'fatalistic' coping styles, low levels of self-efficacy, high levels of stigma and low levels of, or low satisfaction with, social support. Further research is needed both to assess the level of psychological distress in patients following the diagnosis and treatment of colorectal cancer, and to clarify the association with the factors considered to increase vulnerability to psychological distress.

1.6 Rationale for this study

The preceding review highlights the fact that colorectal cancer is a major health problem for men and women today. It is also one of several site-specific cancers that patients are likely to survive beyond five years of diagnosis. Thus, there is a clear need for further research into the psychological impact of colorectal cancer diagnosis and treatment.

Although bowel surgery in general, and stoma surgery in particular, is an intrusive and substantial operation, the evidence suggests that the majority of patients show good psychological adjustment post-surgery. Further research efforts need to be directed at identifying those subgroups that are most vulnerable to the adverse psychological sequelae of this disease and its treatment. Therefore, there is a need to identify the biological, psychological and social factors that may increase the risk of psychological distress. A factor of particular interest are today's more intensive treatment approaches, which employ advanced sphincter-saving surgical techniques as standard, as contrary to initial hopes, these procedures may not automatically lead to better psychological adjustment.

The current study will focus on post-surgical colorectal cancer patients, rather than a heterogeneous cancer population, as the evidence highlights that psychological distress may vary according to the specific diagnoses and treatments (Anderson, 1994). As the evidence also suggests that psychological distress may vary in palliative/ 'non-cured' patients (Vachon, 1993), the current study will focus upon the primary operable colorectal cancer population (i.e. Dukes stage A to C). The current study will focus upon psychological adjustment from 1 year post-surgery⁷ as the level of psychological distress also varies according to time since diagnosis and treatment (Whynes and Neilson, 1997). A limitation in previous research has been the use of various, study-specific measures (Sprangers *et al.*, 1995); therefore, standardised measures will be employed in this study where possible. The development of more sophisticated measures for use with this population (e.g. the Mental Adjustment to Cancer Scale: Watson, Greer & Bliss, 1989) provides an opportunity to evaluate the issues further.

1.7 Research questions

The current study aims to complete an up-to-date evaluation of:

- What is the level of psychological distress, particularly anxiety and depression, in men and women who have undergone surgery for colorectal cancer?
- What factors are associated with the level of psychological distress in men and women who have undergone surgery for colorectal cancer? The factors to be explored include demographic variables, disease and treatment variables, and psychological and social mediating variables.

⁷ In terms of physical functioning, bowel function typically stabilises six months to 1 year after surgery (Frigell, Ottander, Stenbeck & Pahlman, 1990).

A secondary aim of the study is to explore patient perceptions of, and satisfaction with, care during diagnosis and treatment.

1.8 Hypotheses

- 1) There will be higher levels of psychological distress (anxiety and depression) in a subgroup of patients following surgery for colorectal cancer according to a range of demographic, disease and treatment factors as follows:**
 - a) There will be higher levels of psychological distress (anxiety and depression) in those who are younger and female.**
 - b) There will be higher levels of psychological distress (anxiety and depression) in those who are single, live alone, have fewer years in education and are of lower socioeconomic status.**
 - c) There will be higher levels of psychological distress (anxiety and depression) in those with concurrent physical health problems, a history of psychiatric problems and concurrent life events.**
 - d) There will be higher levels of psychological distress (anxiety and depression) in those with a family history of colorectal cancer and with advanced disease severity at diagnosis.**
 - e) There will be higher levels of psychological distress (anxiety and depression) in those who had permanent stoma surgery and additional adjuvant therapy (i.e. chemotherapy and/ or radiotherapy). The relationship between level of psychological distress and time since surgery will also be explored.**

- 2) There will be higher levels of psychological distress (anxiety and depression) in those with lower 'fighting spirit', higher 'helplessness/ hopelessness', higher 'anxious pre-occupation' and higher 'fatalistic' coping styles. The relationship between level of psychological distress and 'avoidance' will also be explored.
- 3) There will be higher levels of psychological distress (anxiety and depression) in those with lower levels of generalised self-efficacy.
- 4) There will be higher levels of psychological distress (anxiety and depression) in those with higher levels of stigma.
- 5) There will be higher levels of psychological distress (anxiety and depression) in those with a lower number of, and/or less satisfaction with, social support.

2. METHOD

After describing the study design, the criteria for participant inclusion will be summarised. This will be followed by a description of the measures used, an outline of the procedure and a discussion of the key ethical issues.

2.1 Design

A cross-sectional, correlational design was used to explore the level of psychological distress in colorectal cancer patients post-surgery.

2.2 Participants

Participants were male and female NHS patients under the care of consultant surgeons at a general hospital. The inclusion criteria were as follows:

- primary operable colorectal cancer (Dukes stage A, B and C).
- surgical treatment involving resection, temporary or permanent colostomy.
- 12-24 months post-surgery.
- no current inpatient treatment or palliative care.

2.3 Measures

2.3.1 Background information

A series of questions concerned participants age, marital status, domestic status (i.e. living circumstances), years in education, occupation and family history of colorectal cancer (see question schedule in Appendix 1.1). Details regarding concurrent physical

health problems, history of psychiatric problems and concurrent stressful life events in addition to cancer were also noted. For each participant, details of surgical and adjuvant treatment, and Dukes stage of cancer at diagnosis (i.e. disease severity) were collated from medical records.

2.3.2 Questionnaires

The Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983)

The Hospital Anxiety and Depression Scale is a 14 item scale developed specifically for use with medical populations (see Appendix 1.2). It excludes somatic items, with the exception of 'I feel as though I am slowed down'. It consists of two subscales, one measuring anxiety (7 items) and one measuring depression (7 items), which are scored separately. Each item is scored from 0 to 3. For each subscale, total scores range from 0 to 21. Scores of 8-10 are taken to indicate 'possible cases', whilst scores of 11 and above are taken to indicate 'cases' (Zigmond & Snaith, 1983).

Internal consistency has been assessed for each of the two subscales with Cronbach's alpha values as follows: anxiety = 0.93; depression = 0.90 (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991). Concurrent validity was demonstrated by comparison with a 5 point psychiatric rating scale for 100 medical outpatients, with which the HADS subscales correlated significantly (r values for anxiety = 0.54 and depression = 0.79; Zigmond & Snaith, 1983).

The HADS has been validated on a cancer patient sample (Razavi, Delvaux, Farvacques & Robaye, 1990). It is considered to be particularly appropriate for cancer patients, and

has been used in a number of studies of colorectal cancer patients (e.g. Nordin & Glimelius, 1997).

The Mental Adjustment to Cancer Scale (MAC: Watson, Greer & Bliss, 1989)

The Mental Adjustment to Cancer Scale is a 40 item scale developed to assess coping 'adjustment' or responses to the diagnosis of cancer (Watson, Greer, Young, Inayat, Burgess & Robertson, 1988) (see Appendix 1.3). It is used as a measure of coping styles employed by people with cancer. Respondents are asked to read a number of statements that describe individuals' reactions to having cancer, and to rate each according to how much the statement applies on a 4-point scale ranging from 'definitely does not apply' (1) to 'definitely does' (4).

The items are allocated to five subscales: 'Fighting Spirit' (16 items), 'Helplessness/Hopelessness' (6 items), 'Anxious Preoccupation' (9 items), 'Fatalistic' (8 items) and 'Avoidance' (1 item). Scores on each subscale indicate the extent to which a particular coping style is employed. Clinical 'cases' are defined as individuals with a score of 47 or less on fighting spirit in combination with a score of 12 or more on the helplessness/hopelessness subscale.

Internal consistencies of the various subscales are acceptable, with alpha values as follows: fighting spirit = 0.84, anxious preoccupation = 0.65, fatalistic = 0.65 and helplessness/hopelessness = 0.79 (Watson *et al.*, 1988). Inter-rater reliability (between patients and their partners) is also acceptable with *r* values ranging between 0.63-0.76, with the exception of the single-item avoidance subscale (Watson *et al.*, 1988). Concurrent

validity has been tested by obtaining correlations between MAC subscales and HADS anxiety and depression subscale scores. Highly significant relationships between HADS anxiety and anxious preoccupation ($r = 0.19$), and between HADS depression and helplessness/ hopelessness ($r = 0.19$) and fatalistic ($r = 0.20$) subscales have been found (Watson *et al.*, 1988).

The Generalised Self-Efficacy Scale (GSES: Schwarzer, 1992)

The Generalised Self-Efficacy Scale is a 10 item scale developed to assess the strength of an individual's belief in his or her own ability to respond to novel or difficult situations and to deal with any associated obstacles or setbacks (see Appendix 1.4). There is a four choice response for each item from 'not at all true' (1) to 'exactly true' (4). The total score reflects the strength of an individual's generalised sense of self-efficacy.

This is a new measure that has only been tested formally on German populations so far. High internal consistency ratings have been found, with alpha values ranging between 0.82-0.93, together with high test-retest reliability (Schwarzer, 1992). This measure was chosen because it generates a measure of generalised, as opposed to situation-specific, self-efficacy beliefs.

A self-rating measure of stigma (MacDonald and Anderson, 1984)

The self-rating measure of stigma is a five item scale that was developed to measure participants' perception of stigma (see Appendix 1.5). Statements about avoidance of others, avoidance by others, feelings of self-consciousness, feelings of unattractiveness

and feelings of difference are rated from ‘complete disagreement’ (0) to ‘complete agreement’ (3). The scale is supported by three additional questions about perceptions of change since surgery; in self-esteem, in physical appearance, and in married life.

This measure of stigma was chosen because, first, it had been developed for use with patients with colorectal cancer, and second, there are few other measures of stigma available. However, there are no norms for this measure and no cut-off point based on total scores. To analyse the data in their original study, the authors compared the extremes: 0 or 1 (‘negligible stigma’) against 2 or 3 (‘some stigma’).

The Short Form Social Support Questionnaire (SSQ6: Sarason, Shearin, Pierce & Sarason, 1987a)

The Short Form Social Support Questionnaire is a six item version of the original 27 item Social Support Questionnaire (Sarason, Levine, Basham & Sarason, 1983) (see Appendix 1.6). It is used to provide information about the amount of support available to an individual and their satisfaction with this. The SSQ6 yields one quasi-structured measure (SSQ6-n: number of supports); up to nine individuals can be listed for each question. It also yields one global functional measure (SSQ6-s: satisfaction with support); for each question, respondents rate their satisfaction with the identified type of support ranging from ‘very dissatisfied’ (1) to ‘very satisfied’ (6).

There are no norms for the SSQ6 and therefore the scores provide relative measures only, which can be used as dependent or independent variables in studies. Both the number and satisfaction subscales show high internal consistency, with alpha values

ranging between 0.90-0.93, and high test-retest reliability (Sarason, Shearin, Pierce and Sarason, 1987a). The validity of the original scale is well-documented (Sarason *et al.*, 1983).

2.3.3 Open-ended questions

A series of open-ended questions were developed to explore the individual's experience in terms of their presenting symptoms, receiving a diagnosis of colorectal cancer and undergoing treatment. The five open-ended questions were as follows:

1. Before you received your diagnosis, how serious did you think your symptoms were?

Note. The delay between first noticing the symptoms and seeking medical advice was also to be noted.

2. Following your diagnosis, how did you think you would cope?
3. How satisfied were you with the information you received about your condition and the treatment?
4. How satisfied were you with the treatment?
5. How could the service be improved: with hindsight, are there any ways that you think things could have been easier for you?

The first four questions were supplemented by 10-point rating scales. A copy of the question schedule can be found in Appendix 1.7.

2.4 Procedure

2.4.1 Liaison with professionals involved

Initial meetings were held with the clinical psychology services manager to discuss the project. Regular meetings were subsequently held with the consultant colorectal

surgeon to discuss the research protocol and obtain his approval to proceed. The other consultant colorectal surgeons at the hospital were notified of the project and the researcher met with the cancer care nursing team to discuss the project further. The consent of all relevant professionals was obtained before proceeding with an application to the local research ethics committee.

2.4.2 Ethics approval

Ethical approval was sought from the local research ethics committee. The application was approved, subject to the following condition: although general practitioner (GP) approval was not deemed necessary, GP's were to be informed regarding their patients who had participated in the study (see letter of approval in Appendix 2).

2.4.3 Recruitment

A list of patients who had been diagnosed with colorectal cancer in the last 12-24 months was obtained from the histopathology department. A list of patients who had undergone a surgical procedure used in the treatment of colorectal cancer was obtained from the theatre records department. The patients with a diagnosis, type and date of surgical treatment that met the inclusion criteria were thus identified. The hospital computer records system was then used to identify and exclude those patients who were currently receiving inpatient treatment, or who had recently deceased.

A patient information sheet, with a reply-slip and pre-paid envelope enclosed, was then sent to each of the patients meeting the inclusion criteria (see Appendix 3.1). The information sheet explained the aims of the study and invited them to participate. It also

emphasised that the study was entirely voluntary and that the patients' decision about participating would not affect their access to medical or psychological care in any way.

Those patients who returned the reply slip indicating that they were interested in the study were then contacted by telephone. The study was explained in more detail and the patient was given the opportunity to ask questions. If the patient agreed to proceed, the researcher arranged a convenient time to meet with them either at their home or at the hospital. Personal safety procedures were adhered to and a diary of appointments was kept with supporting colleagues.

For patients who did not return the reply slip (i.e. at least 1 month following the initial correspondence), the hospital computer records were checked again to ensure that the inclusion criteria were still met. A follow-up letter (see Appendix 3.2) was then sent.

2.4.4 Interviews

At the start of the interview, the purpose of the study and the procedure was explained to potential participants and they were encouraged to ask any questions. If they wished to proceed they were then asked to complete a written consent form (see Appendix 4). Participants were then shown a copy of the GP information sheet (see Appendix 3.3) and permission was sought to inform their GP about the study.

A brief explanation of each measure was followed by the completion of the background information, each of the questionnaires and the open-ended questions. The procedure took 1-1½ hours in total. Throughout the interview it was made clear that participants

were free to choose whether or not they wanted to proceed. At the end of the interview participants were debriefed and given the opportunity to ask questions and discuss any concerns that had arisen. They were also reminded that they could contact the researcher or her supervisor at any time.

Following the interview, with the participant's permission, their GP was sent an information letter to inform them about the study and their patient's participation.

2.4.5 Feedback

Each of the participants will be sent a letter of thanks which summarises the research study.

2.5 Ethical issues

Efforts were made to ensure that participants' were aware of the confidentiality and anonymity of the study, and that they could decline to participate at any stage. A contingency plan was formulated for participants who showed symptoms of psychological distress, either preceding the study or as a result of issues arising during the study. It was agreed that any concerns would be discussed with the participant and the supervisor and appropriate action would be taken according to the individual case. This may involve liaison with the GP, the consultant surgeon or the colorectal nurse specialist.

3. RESULTS

After a brief outline of the data analysis, the characteristics of the sample will be described. The investigation of the hypotheses will then be reported. This will be followed by a description of the other findings of interest and the qualitative findings.

3.1 Data analysis

The analyses were performed using the statistical package SPSS (SPSS, Inc., 1997). Descriptive statistics were performed on a range of variables. Before hypothesis testing, checks for normality of distribution were made on each variable using the Kolmogorov-Smirnov test. Where the data failed to meet the assumptions of normality necessary for parametric statistics, non-parametric tests were used. Where the predicted direction of difference was stated in the hypothesis, one-tailed tests were used; otherwise two-tailed tests were used.

Non-parametric analyses were used primarily to test the hypotheses. Differences between two groups were tested using the Mann Whitney U test and differences between more than two groups were investigated using the Kruskal-Wallis chi-square test⁸. The magnitude of relationship between two variables was investigated using a correlation coefficient (e.g. Pearson's). Scatterplots were used to ascertain the relationship between the variables and to determine the most appropriate correlation coefficient (see Appendix 5). Multiple regression analyses were also completed in order

⁸ Where descriptive statistics are shown to summarise the differences between groups, the mean value of central tendency is used. However, it is noted that non-parametric tests analyse the difference between groups based on mean rank scores.

to assess which variables may predict level of psychological distress.

3.2 The characteristics of the sample

3.2.1 Response rate

A total of 55 men and women were sent patient information sheets. Of these, 36 individuals returned the reply slip indicating that they were willing to participate in the study. Sixteen individuals indicated that they did not wish to take part and three individuals did not respond either to the Patient Information Sheet or to a follow-up letter. Of those agreeing to take part, three individuals were unable to do so due to events unrelated to the study. Table 2 shows the breakdown of the number of patients who participated from the original population of people who were contacted.

Table 2. Number of patients participating from original population

Sent Information	Unwilling to participate	Unable to participate	No reply	Participated	Response rate
55	16	3	3	33	60%

Of those who did participate, 24 completed the interview alone, whilst nine had their spouse or other relative present. Most interviews were completed at the participants home; four participants chose to be interviewed at the hospital.

3.2.2 Demographic characteristics

Of the 33 participants, 17 (51.5%) were men and 16 (48.5%) were women. The mean age of participants was 71.9 years (SD = 9.44; range = 48-87). In the general population, the median age at diagnosis is 70 years (Cancer Guidance Sub-Group of the

Clinical Outcomes Group, 1997). In this sample, the median age⁹ was 72 years (men = 72 years; women = 77 years). Nineteen participants (57.6%) were married and 14 (42.4%) were single, widowed, divorced or separated. Twenty-one participants (63.6%) were living with their spouse or partner, of which three also had children living with them, and 12 (36.4%) were living alone.

Socioeconomic status was classified using the registrar general's classification method (Office of Population Censuses and Surveys, 1990) based upon the participants occupation. The limitations of classifying participants in this way are acknowledged (Mascie-Taylor, 1990). Fourteen participants (42.4%) were in socioeconomic classes I and II, and 19 (57.6%) were in classes III, IV and V. Nineteen participants (57.6%) had been in education up to the age of 16 years, and 14 (42.4%) had been in education beyond the age of 16. The majority of the sample were white British (96.9%); one participant was born in Algeria.

Twenty-three participants (69.7%) reported at least one other concurrent physical health problem (range = 1-3) (e.g. arthritis, high blood pressure). Five participants (15.2%) reported a history of psychiatric problems for which they had sought professional help. Twenty-two participants (66.6 %) reported at least one other concurrent life event in addition to cancer (range = 1-4) (e.g. bereavement).

⁹ Age in this sample referred to participant's current age, that is 12-24 months after diagnosis and surgery.

3.2.3 Disease and treatment characteristics

Disease characteristics

After first noticing their symptoms, the mean patient delay before consulting their GP was 6.4 weeks (SD = 7.99; range = 0-24 weeks); five participants had their symptoms identified during routine medical check-up appointments. 27.3 per cent of the sample had either a condition known to predispose them to developing colorectal cancer (e.g. diverticulitis) (three participants) or a family history of colorectal cancer (six participants). There were also seven participants (21.2%) who had a family history of other types of cancer.

In terms of the severity of cancer at diagnosis, Table 3 shows the distribution of Dukes stages at diagnosis in this sample, alongside general population estimates (Cancer Guidance Sub-Group of the Clinical Outcomes Group, 1997). Disease severity was also categorised into non-advanced cancer (Dukes stage A and B) (69.7%) and advanced cancer (Dukes stage C and D) (30.3%).

Table 3. Disease severity at diagnosis (Dukes stage)

Dukes stage	N	Current study sample	General population estimates
A	2	6.1%	11%
B	21	63.6%	35%
C	10	30.3%	26%
D	-	-	29%

Treatment characteristics

The mean time since surgery was 15.76 months (SD = 3.79; range = 12-24). Of the 33 participants, six (18.2%) required temporary stomas and five (15.2%) required

permanent stomas. Eight participants (24.2%) received chemotherapy of whom three (9.1%) also received radiotherapy.

Four participants (12.1%) experienced disease related complications (e.g. recurrence of cancer; incomplete removal of tumour; course of chemotherapy not completed). Seven participants (21.2%) experienced complications relating to their treatment (e.g. infection on wound; infection necessitating isolation; osteomyelitis in spinal cord). One participant experienced both types of complication.

3.2.4 Comparison of participants and non-participants

The participating sample was compared to the group of patients who were unwilling to participate in the study on a range of demographic, disease and treatment characteristics¹⁰ (see Table 4).

A t-test for independent samples (two-tailed) showed that there was no significant difference between groups in the proportion of men and women ($t = -.10$, d.f. = 47, n.s.). The mean age was very similar for non-participants and participants, and a t-test for independent samples (two-tailed) confirmed that there was no significant difference between groups ($t = .33$, d.f. = 47, n.s.). A Mann-Whitney U test for non-parametric data showed that there was a significant difference between the groups in marital status ($U = 185.0$, $p < .05$, one-tailed); that is, there was a greater proportion of single, widowed, divorced or separated people in the participant group.

¹⁰ In comparisons between the participants and non-participants, parametric tests (e.g. t-tests) were used where the data met the assumptions of normality.

Table 4. Comparison of participants and non-participants on demographic, disease and treatment characteristics

	Participants	Non-participants
Gender: <i>N</i> (%)		
- men	17 (51.5%)	8 (50%)
- women	16 (48.5%)	8 (50%)
Age (years)		
- mean (SD)	71.88 (9.44)	70.88 (11.45)
- range	48-87	43-91
Marital status: <i>N</i> (%)		
- married	19 (57.6%)	14 (87.5%)
- single, widowed, separated	14 (42.4%)	2 (12.5%)
Time since surgery (months)		
- mean (SD)	15.76 (3.79)	17.19 (4.020)
- range	12-24	12-23
Dukes stage: <i>N</i> (%)		
- A	2 (6.06%)	4 (25%)
- B	21 (63.6%)	4 (25%)
- C	10 (30.3%)	8 (50%)

A t-test for independent samples (two-tailed) showed that there was no significant difference between groups in the mean time since surgery ($t = -1.21$, d.f. = 47, n.s.). A Mann-Whitney U test showed that there was no significant difference between groups in advanced disease severity (Dukes stage C vs. A/ B) ($U = 212.0$, n.s., two-tailed).

3.3 Investigation of hypotheses

In the following section, each hypothesis will be re-stated and then followed by the relevant results.

3.3.1 Psychological distress

Hypothesis 1: There will be higher levels of psychological distress (anxiety and depression) in a subgroup of patients following surgery for colorectal cancer according to a range of demographic, disease and treatment factors.

The Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) was used to assess levels of anxiety and depression. Scores of 8-10 are taken to indicate of 'possible cases', whilst scores of 11 and above are taken to indicate 'cases' (Zigmond & Snaith, 1983). The mean score on the HADS anxiety subscale was 3.97 (SD = 2.65; range = 0-9). Two participants (6.1%) scored above the threshold for 'possible cases' of anxiety. The mean score on the HADS depression subscale was 2.39 (SD = 2.14; range = 0-9). One participant (3.0%) scored above the threshold for 'possible cases' of depression.

3.3.2 Demographic variables and psychological distress

Age and gender

Hypothesis 1a: There will be higher levels of psychological distress (anxiety and depression) in those who are younger and/ or female.

The relationship between age and psychological distress was assessed using Pearson's

correlation coefficient (see Appendix 5.1 for scatterplots). There was no significant relationship between HADS anxiety and age ($r = -.25$, n.s., one-tailed). For HADS depression, there was a highly significant relationship with age ($r = .49$, $p < .01$, one-tailed); that is, the older the participant, the higher the level of depression.

The mean anxiety and depression scores (HADS) for men and women can be seen in Table 5. Mann Whitney U tests showed that there were no significant differences between men and women on either HADS anxiety ($U = 128.5$, n.s., one-tailed) or HADS depression ($U = 125.5$, n.s., one-tailed).

Table 5. Mean anxiety and depression scores (HADS) according to gender

Gender	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Men	17	4.11 (2.39)	2.06 (1.52)
Women	16	3.81 (2.97)	2.75 (2.65)

An analysis of covariance¹¹ showed that the interaction of age by gender was not significant for HADS anxiety ($F(1, 29) = 1.49$, n.s.) or HADS depression ($F(1, 29) = 0.343$, n.s.).

Marital status, domestic status, level of education and socioeconomic status

Hypothesis 1b: There will be higher levels of psychological distress (anxiety and depression) in those who are single, live alone, have fewer years in education and are of lower socioeconomic status.

¹¹ As there was no non-parametric equivalent, an analysis of covariance was used. As this is a parametric test, and as the data may not meet the assumptions of normality, the results must be interpreted with caution.

The mean anxiety and depression scores (HADS) according to marital status, domestic status, level of education and socioeconomic class can be seen in Tables 6-9 respectively.

Table 6. Mean anxiety and depression scores (HADS) according to marital status

Marital status	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Married	19	4.32 (2.58)	2.26 (1.99)
Single, widowed or divorced	14	3.50 (2.77)	2.57 (2.38)

Mann Whitney U tests showed that there were no significant differences between groups according to marital status on either HADS anxiety ($U = 111.0$, n.s., one-tailed) or HADS depression ($U = 124.0$, n.s., one-tailed).

Table 7. Mean anxiety and depression scores (HADS) according to domestic status

Domestic status	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Live with relative	12	4.05 (2.64)	2.14 (1.93)
Live alone	21	3.83 (2.79)	2.83 (2.48)

Mann Whitney U tests showed that there were no significant differences between groups according to domestic status in HADS anxiety ($U = 103.0$, n.s., one-tailed) or HADS depression ($U = 121.5$, n.s., one-tailed).

Table 8. Mean anxiety and depression scores (HADS) according to level of education

Level of education	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
<16 years	19	4.32 (2.82)	2.47 (2.14)
>16 years	14	3.50 (2.41)	2.29 (2.20)

Mann Whitney U tests showed that there were no significant differences between groups according to level of education on either HADS anxiety ($U = 109.5$, n.s., one-tailed) or HADS depression ($U = 121.0$, n.s., one-tailed).

Table 9. Mean anxiety and depression scores (HADS) according to socioeconomic status

Socioeconomic status	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
I & II	14	3.86 (2.74)	2.14 (1.66)
III, IV & IV	19	4.05 (2.65)	2.58 (2.46)

Mann Whitney U tests showed that there were no significant differences between groups according to socioeconomic status on either HADS anxiety ($U = 126.0$, n.s., one-tailed) or HADS depression ($U = 127.5$, n.s., one-tailed).

Concurrent physical problems, history of psychiatric problems and concurrent life events

Hypothesis 1c: There will be higher levels of psychological distress (anxiety and depression) in those with concurrent physical health problems, a history of psychiatric problems and concurrent life events.

The mean anxiety and depression scores (HADS) according to the presence of

concurrent physical health problems, history of psychiatric problems and concurrent life events can be seen in Tables 10-12 respectively.

Table 10. Mean anxiety and depression scores (HADS) according to concurrent physical health problems

Concurrent physical health problems	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
At least one	23	3.30 (2.40)	2.74 (2.28)
No	10	5.50 (2.68)	1.60 (1.58)

Mann Whitney U tests showed that there was no significant difference between groups according to the presence of concurrent physical health problems in HADS depression ($U = 81.0$, n.s., one-tailed). There was a significant difference in HADS anxiety ($U = 60.0$, $p < .05$, one-tailed); that is, participants who had no concurrent physical health problems showed significantly higher levels of anxiety than participants with at least one concurrent physical health problem.

Table 11. Mean anxiety and depression scores (HADS) according to history of psychiatric problems

History of psychiatric problems	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Yes	5	3.80 (1.30)	3.80 (3.35)
No	28	4.00 (2.84)	2.14 (1.81)

Mann Whitney U tests showed that there were no significant differences between groups according to the presence of a history of psychiatric problems on either HADS anxiety ($U = 67.0$, n.s., one-tailed) or HADS depression ($U = 49.0$, n.s., one-tailed).

Table 12. Mean anxiety and depression scores (HADS) according to concurrent life events

Concurrent life events	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
At least one	22	4.27 (2.41)	2.68 (2.48)
None	11	3.36 (3.11)	1.82 (1.08)

Mann Whitney U tests showed that there were no significant differences between groups according to the presence of concurrent life events (other than cancer) in HADS anxiety ($U = 94.5$, n.s., one-tailed) or HADS depression ($U = 107.0$, n.s., one-tailed).

3.3.3 Disease and treatment variables and psychological distress

Family history of colorectal cancer and advanced disease severity

Hypothesis 1d: There will be higher levels of psychological distress (anxiety and depression) in those with a family history of colorectal cancer and with advanced disease severity at diagnosis.

The mean anxiety and depression scores (HADS) for participants who had a family history of colorectal cancer, a family history of other types of cancer, or no known family history can be seen in Table 13.

Table 13. Mean anxiety and depression scores (HADS) according to family history of cancer

Family history	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Colorectal cancer	6	3.00 (2.37)	3.16 (2.79)
Other cancer	7	3.42 (3.21)	2.29 (1.80)
None	20	4.45 (2.54)	2.20 (2.09)

Kruskal-Wallis chi-square tests showed that there were no significant differences between groups in either HADS anxiety ($\chi^2 = 1.80$, d.f. = 2, n.s.) or HADS depression ($\chi^2 = 0.61$, d.f. = 2, n.s.). The data for participants with a family history of colorectal or another type of cancer was then combined, and compared with participants with no family history of cancer. No significant difference was found for either HADS anxiety ($U = 95.0$, n.s., one -tailed) or HADS depression ($U = 113.0$, n.s., one-tailed).

As there were so few participants with Dukes stage A colorectal cancer ($N = 2$), participants were grouped according to whether the disease was classified as not advanced (stages A and B) or advanced (stage C); the mean anxiety and depression scores (HADS) can be seen in Table 14.

Table 14. Mean anxiety and depression scores (HADS) according to whether disease was classified as advanced at diagnosis

Advanced disease classification	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Yes (C)	10	4.60 (2.41)	3.50 (2.51)
No (A, B)	23	3.70 (2.75)	1.91 (1.81)

Mann Whitney U tests showed that there was no significant difference between groups in HADS anxiety ($U = 94.5$, n.s., one-tailed). However, HADS depression was significantly higher in the advanced disease severity group ($U = 66.0$, $p < .05$, one-tailed).

Type of surgery, adjuvant therapy and time since surgery

Hypothesis 1e: There will be higher levels of psychological distress (anxiety and

depression) in those who had permanent stoma surgery and additional adjuvant therapy (i.e. chemotherapy and/ or radiotherapy). The relationship between level of psychological distress and time since surgery will also be explored.

The mean anxiety and depression scores (HADS) for participants who required permanent, temporary or no stoma surgery can be seen in Table 15. Kruskal-Wallis chi-square tests showed that there were no significant differences between groups in either HADS anxiety ($\chi^2 = 0.16$, d.f. = 2, n.s.) or HADS depression ($\chi^2 = 0.55$, d.f. = 2, n.s.).

Table 15. Mean anxiety and depression scores (HADS) according to type of surgery

Stoma	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Permanent	5	3.80 (3.03)	2.60 (1.52)
Temporary	6	3.67 (3.01)	2.00 (1.79)
None	22	4.09 (2.60)	2.45 (2.39)

The mean anxiety and depression scores (HADS) for participants according to whether they had adjuvant therapy in addition to surgery can be seen in Table 16. Mann Whitney U tests showed that there were no significant differences between groups on either HADS anxiety ($U = 89.5$, n.s., one-tailed) or HADS depression ($U = 115.5$, n.s., one-tailed).

Table 16. Mean anxiety and depression scores (HADS) according to adjuvant therapy

Adjuvant therapy	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
Yes	11	3.55 (2.67)	2.36 (1.91)
No	22	4.8 (2.52)	2.45 (2.62)

The relationship between time since surgery and psychological distress (HADS anxiety and depression) was assessed using Pearson's correlation coefficient (see Appendix 5.2 for scatterplots). A non-significant result was found for HADS anxiety ($r = .01$, n.s., two-tailed) and for HADS depression ($r = -.14$, n.s., two-tailed).

The results partially supported the first hypothesis. A subgroup of three participants (9.1%) showed higher (i.e. clinically significant) levels of psychological distress, and advanced disease severity was associated with higher levels of depression. However, some findings were contradictory to the hypothesis. First, lower levels of depression were found in younger participants and, second, lower levels of anxiety were found in participants with concurrent physical health problems.

3.3.4 Coping style and psychological distress

Hypothesis 2: There will be higher levels of psychological distress (anxiety and depression) for those with lower 'fighting spirit', higher 'helplessness/ hopelessness', higher 'anxious pre-occupation' and higher 'fatalistic' coping styles. The relationship between level of psychological distress and 'avoidance' will also be explored.

The Mental Attitudes to Cancer scale (MAC: Watson, Greer & Bliss, 1989) was used as a measure of the coping styles employed by participants. Coping skills were assessed using the classifications in the MAC: fighting spirit, anxious preoccupation, fatalistic, helplessness/ hopelessness and avoidance (denial). The mean score obtained across all 33 participants and the range on each of the subscales of the MAC may be seen in Table 17. There was some missing data on the 'avoidance' subscale.

Table 17. Mean score for all 33 participants and range on each subscale of the MAC

Subscale	<i>N</i>	Mean (SD)	Range	Possible Range
‘Fighting spirit’	33	53.67 (5.13)	40-62	16–64
‘Anxious preoccupation’	33	20.48 (3.17)	11-26	6–36
‘Helplessness/ hopelessness’	33	8.48 (2.25)	6–15	6–24
‘Fatalistic’	33	20.58 (2.97)	12-26	8–32
‘Avoidance’	32	1.84 (0.92)	1-4	1–4

‘Cases’ may be defined as individuals with a score of 47 or less on the fighting spirit subscale, in combination with a score of 12 or more on the helplessness/ hopelessness subscale (Watson, Greer & Bliss, 1989). Among the 33 participants, there was one case. The relationship between coping style and psychological distress (HADS anxiety and depression) was assessed using correlation coefficients (see Appendix 5.3 for scatterplots).

‘Fighting spirit’

Pearson’s correlation coefficient was used to assess the relationship between the ‘fighting spirit’ coping style and psychological distress. For HADS anxiety, the result was non-significant ($r = -.21$, n.s., one tailed). For HADS depression, there was a highly significant relationship ($r = -.52$, $p < .001$, one-tailed); that is, participants who scored lower on fighting spirit showed higher levels of depression. Even when the effect of age and advanced disease severity were controlled for (i.e. demographic and disease variables found to have a significant relationship with HADS depression), the relationship between ‘fighting spirit’ and HADS depression remained significant ($r = -$

.41, $p < .05$; one-tailed).

'Anxious preoccupation'

Pearson's correlation coefficient was used to assess the relationship between the 'anxious preoccupation' coping style and psychological distress. For HADS anxiety, the result was significant ($r = .31$, $p < .05$, one tailed); that is, participants who scored higher on anxious preoccupation showed higher levels of anxiety. There was no significant relationship for HADS depression ($r = .13$, n.s., one-tailed). Even when the effect of concurrent physical health problems was controlled for (i.e. a demographic variable found to have a significant relationship with HADS anxiety), the relationship between 'anxious preoccupation' and HADS anxiety remained significant ($r = .29$, $p < .05$, one-tailed).

'Helplessness/ hopelessness'

Pearson's correlation coefficient was used to assess the relationship between 'helplessness/ hopelessness' coping style and psychological distress. For HADS anxiety, the result was not significant ($r = -.10$, n.s., one-tailed). For HADS depression, there was a significant relationship ($r = .46$, $p < .01$, one-tailed); that is, participants who scored higher on helplessness/ hopelessness showed higher levels of depression. Even when the effect of age and advanced disease severity were controlled for (i.e. demographic and disease variables found to have a significant relationship with HADS depression), the relationship between 'helplessness/ hopelessness' and HADS depression remained significant ($r = .41$, $p < .01$, one-tailed).

‘Fatalistic’

Pearson’s correlation coefficient was used to assess the relationship between the ‘fatalistic’ coping style and psychological distress. The result was non-significant for HADS anxiety ($r = -.20$, n.s., one-tailed) and for HADS depression ($r = .24$, n.s., one-tailed).

‘Avoidance’

The avoidance subscale was derived from only one item on the MAC. As very few participants rated this item as ‘3’ (applies) or ‘4’ (definitely applies), the data was it was amalgamated to even out the sample size. Thus, scores of ‘3’ and ‘4’ were combined and compared with the more frequent ratings of ‘1’ (definitely doesn’t apply) and ‘2’ (doesn’t apply). The mean anxiety and depression scores according to ratings of ‘avoidance’ can be seen in Table 18.

Table 18. Mean anxiety and depression scores (HADS) according to rating of ‘avoidance’ item (MAC)

Rating of ‘Avoidance’ item	<i>N</i>	Anxiety mean (SD)	Depression mean (SD)
‘Applies’ or ‘Definitely applies’	7	4.43 (3.41)	2.14 (3.13)
‘Does not apply’	11	4.64 (2.25)	3.18 (1.89)
‘Definitely does not apply’	14	3.50 (2.47)	1.86 (1.75)

Kruskal-Wallis chi-square tests showed that there were no significant differences between groups according to ‘avoidance’ in either HADS anxiety ($\chi^2 = 1.29$, d.f. = 2, n.s.) or HADS depression ($\chi^2 = 4.47$, d.f. = 2, n.s.).

The second hypothesis is therefore partially supported, in that higher levels of depression were associated with lower 'fighting spirit' and higher 'helplessness/hopelessness' coping styles; and higher levels of anxiety were associated with higher 'anxious preoccupation' coping styles.

3.3.5 Self-efficacy and psychological distress

Hypothesis 3: There will higher levels of psychological distress (anxiety and depression) for those with lower levels of generalised self-efficacy.

The Generalised Self-Efficacy Scale (GSES: Schwarzer, 1992) was used to assess self-efficacy. This measure yields one overall score (possible range = 10-40); high scores are indicative of high self-efficacy, and vice versa. The mean score on the GSES across all participants was 33.91 (SD = 3.06, range = 29-39).

Pearson's correlation coefficient was used to investigate the relationship between self-efficacy and psychological distress (see Appendix 5.4 for scatterplots). The result was non-significant for both HADS anxiety ($r = -.17$, n.s., one-tailed) and HADS depression ($r = .16$, n.s., one-tailed).

The results therefore do not support the third hypothesis.

3.3.6 Stigma and psychological distress

Hypothesis 4: There will be higher levels of psychological distress (anxiety and depression) for those with higher levels of stigma.

The self-rating measure of stigma (MacDonald and Anderson, 1984) was used to assess participants' perception of stigma. This measure yields scores on eight items; higher scores are indicative of high stigma, and vice versa. The first five items are rated on a four point scale ranging from '0' (complete disagreement) to '3' (complete agreement). The last three items are rated as '0' (no) or '1' (yes). To analyse the data in the original study, MacDonald and Anderson (1984) used the extremes: '0 or 1' ('negligible stigma') against '2 or 3' ('some stigma'). However as most of the ratings on items 1-5 were either '0' or '1' in this sample, an alternative method was used. To analyse the stigma data in the current study, ratings of '1', '2' and '3' were amalgamated (i.e. 'some stigma') and compared with ratings of '0' (i.e. 'no stigma') (see Table 19). This method allowed for some comparison to be made in the stigma data, although the results would not be strictly comparable with the findings of MacDonald and Anderson (1984). There was missing data (i.e. no reply) for two items (6 and 8).

Table 19. Frequency of 'no stigma' and 'some stigma' ratings on self-rating measure of stigma

Item	Range	'No stigma' N (%)	'Some stigma' N (%)	No reply N (%)
1. 'Avoidance of others'	0-3	31 (93.9%)	2 (6.1%)	-
2. 'Avoidance by others'	0-1	32 (97.0%)	1 (3.0%)	-
3. 'Feel less attractive'	0-3	27 (81.8%)	6 (18.2%)	-
4. 'Feel odd & different'	0-3	30 (90.9%)	3 (9.1%)	-
5. 'Feel self-conscious'	0-3	31 (93.9%)	2 (6.1%)	-
6. 'Feel worse about self'	0-1	29 (87.9%)	3 (9.1%)	1 (3.0%)
7. 'Change in appearance'	0-1	29 (87.9%)	4 (12.1%)	-
8. 'Change in married life'	0-1	19 (57.6%)	1 (3.0%)	13 (39.4%)

The mean rank anxiety and depression scores (HADS) according to ratings on each of the stigma items can be seen in Table 20.

Table 20. Mean rank anxiety and depression scores (HADS) on each item of the self-rating measure of stigma & Mann Whitney U test statistic

Item No.	N	Anxiety - mean rank			Depression - mean rank		
		No stigma	Some stigma	U	No stigma	Some stigma	U
1	33	16.40	26.25	12.5	17.19	14.00	25.0
2	33	17.00	17.00	16.0	16.50	33.00	0.00*
3	33	17.11	16.50	78.0	15.37	24.33	37.0 *
4	33	17.10	16.00	42.0	17.67	10.33	25.0
5	33	16.40	26.25	12.5	16.94	18.00	29.0
6	32	15.60	25.17	17.5*	16.50	16.50	43.5
7	33	16.84	18.13	53.5	16.74	18.88	50.5
8	20	10.58	9.00	8.0	10.16	17.00	3.0

* $p < .05$

Mann Whitney U tests were used to test for differences between ‘no stigma’ and ‘some stigma’ groups in psychological distress (see Table 20). For HADS anxiety, one significant difference was found on item 6; that is, participants who reported some stigma in terms of “feeling worse about myself” showed higher levels of anxiety than those who reported no stigma. For HADS depression, two significant differences were found between ‘no stigma’ and ‘some stigma’ groups on item 2 and item 3. That is, participants who reported some stigma in terms of “feeling that other people are

avoiding me” or “feeling less attractive than I used to” showed higher levels of depression than those who reported no stigma.

These results lend some support to the fourth hypothesis in that higher levels of depression were associated with higher ratings of stigma in terms of “feeling that other people are avoiding me” and “feeling less attractive”; and higher levels of anxiety were associated with higher ratings of stigma in terms of “feeling worse about myself”. However, these results should be considered very cautiously for two reasons. First, those participants who rated ‘some stigma’ constituted a very small sample size (see Table 19). Second, due to the use of non-parametric tests, it was not possible to rule out whether the significant findings were due to an association with demographic and disease variables found to have a significant relationship with HADS anxiety and depression.

3.3.7 Social support and psychological distress

Hypothesis 5: There will be higher levels of psychological distress (anxiety and depression) in those with a lower number of, and/or less satisfaction with, social support.

Social support was assessed using the Social Support Questionnaire (SSQ6: Sarason, Shearin, Pierce & Sarason, 1987a). This yields two measures; the mean number of supports and the mean satisfaction with supports. The mean number of supports across the 33 participants was 3.18 (SD = 2.31, range = 0.17-9). The mean satisfaction with supports across the 30 participants was 5.83 (SD = 0.31, range = 4.8-6). Correlation

coefficients were used to investigate the relationship between social support and psychological distress (see Appendix 5.5 for scatterplots).

Number of supports

Pearson's correlation coefficient was used to assess the relationship between mean number of supports and psychological distress. No significant relationship was found for HADS depression ($r = -.18$, n.s., one-tailed). However, a significant result was found for HADS anxiety ($r = .30$, $p < .05$, one-tailed). However, when the effect of concurrent physical health problems was controlled for (i.e. a demographic variable found to have a significant relationship with HADS anxiety), the result was no longer significant ($r = .25$, n.s., one-tailed).

Satisfaction with supports

Due to the limited variability between scores, Kendall's correlation coefficient was used to assess the relationship between mean satisfaction with supports and psychological distress. No significant relationship was found for HADS anxiety ($r = -.04$, n.s., one-tailed) or for HADS depression ($r = .11$, n.s., one-tailed).

The fifth hypothesis was therefore not supported by the results. Moreover, one finding was contradictory to the hypothesis. There was weak support that lower levels of anxiety were associated with a lower number of social supports, although this may have been due to an association with a demographic variable.

3.4 Other findings of interest

3.4.1 Multiple regression analyses

Multiple regression analyses were used to investigate which variables contributed most to the level of psychological distress, with HADS anxiety and then HADS depression as the dependent variable. As a multiple regression analysis is a parametric test, the unstandardised residuals of the dependent variable were tested to see if they differed significantly from a normal distribution. Kolmogorov-Smirnov tests indicated that there was no significant difference for either HADS anxiety or HADS depression.

The independent variables¹² were entered into a stepwise regression analysis to take account of any co-linearity between the independent variables. With HADS anxiety as the dependent variable, the following variables were entered: concurrent physical health problems, anxious preoccupation (MAC) and number of social supports (SSQ6). Concurrent physical health problems was the only variable found to contribute significantly to the variance ($R^2 = .15$, d.f. = 1, 31; $F = 5.44$; $p < .05$).

With HADS depression as the dependent variable, the following variables were entered: age, advanced disease classification, fighting spirit (MAC) and helplessness/hopelessness (MAC). Fighting spirit was the only variable found to contribute significantly to the variance ($R^2 = .27$, d.f. = 1, 31; $F = 11.57$; $p < .01$).

¹² Independent variables included those found to have significant relationship with the test variable, and those from reliable measures.

3.4.2 Ratings on open-ended questions

All participants were asked a series of open-ended questions regarding presenting symptoms, receiving diagnosis and undergoing treatment. The first four questions were supplemented by 10-point rating scales. This section summarises these quantitative ratings; the qualitative reports are summarised in Section 3.5.

Subjective seriousness of symptoms

Participants rated how serious they considered their symptoms to be before they were given their diagnosis of colorectal cancer from 'not serious at all' (1) to 'very serious' (10). The mean rating was 4.79 (SD = 3.22; range = 1-10).

Subjective ability to cope

Participants rated how well they thought they would cope following their diagnosis of colorectal cancer, from 'not cope at all' (1) to 'cope very well'(10). The mean rating was 7.75 (SD = 2.48; range = 1-10).

Satisfaction with information given regarding condition and treatment

Participants rated how satisfied they were with the information that they received about their condition and the treatment from 'not satisfied at all' (1) to 'very satisfied' (10). The mean rating was 9.55 (SD = 1.23; range = 5-10).

Satisfaction with treatment

Participants rated how satisfied they were with their treatment from 'not satisfied at all' (1) to 'very satisfied' (10). The mean rating was 9.48 (SD = 1.25; range = 5-10).

3.5 Qualitative findings

The following section summarises responses to the last open-ended question ('How could the service be improved: with hindsight, are there any ways that you think things could have been easier for you?'). Additional qualitative information prompted by the first four open-ended questions is also included. Four main themes emerged including comments about the following:

- community care preceding diagnosis;
- inpatient hospital care by the specialist surgical and oncology teams, and the general ward teams;
- community care and outpatient care post-surgery, including GP teams and counselling helplines;
- communication about diagnosis and/ or treatment.

The open-ended questions also prompted participants to comment upon what they considered to be strengths of the service. Therefore the qualitative information was separated into comments identifying areas for improvement in the service, and comments highlighting areas of strength. Table 21 shows the frequency of each category of responses.

Table 21. Frequency of each category of participant comments regarding areas of strength and areas for improvement in the service

Category of comments	No. participants highlighting as area of:	
	Improvement	Strength
Community care pre-diagnosis	6	1
Inpatient care: specialist/ general	4/ 10	23/ 17
Community & outpatient care post-surgery	6	9
Communication around diagnosis & treatment	12	19

Some examples of participant comments are summarised below: first, areas for service improvement; and second, areas of service strength.

3.5.1 Participant comments about areas for service improvement

Community care preceding diagnosis

‘why don’t they do blood tests for cancer’

‘it was only when I saw a different doctor that my symptoms were picked up and I was referred on’

‘it took a long time to get referred to a specialist 2 years I had to go to my doctor and say that this has been going on for a long time’

‘further investigation could have been done earlier rather than prescribing me painkillers’

‘I had terrible piles I visited the doctors twice over Christmas and was not examined once later I was told ‘you should have come earlier’

Inpatient hospital care: specialist surgical and oncology teams

‘I would have liked less “hand-wringing” in the voice; this suggests you’re at death’s door’

‘during chemotherapy, they couldn’t get the needles in it took four goes’

‘the wound was not dressed properly it had to be re-opened’

Inpatient hospital care: general ward teams

‘there was a shortage of nurses’

‘I had to sneak into the treatment room to change the dressing on my wound myself’

‘the nursing care was non-existent when I was put into isolation for five days sheets not changed, food pushed through door on a tray, couldn’t get assistance’

‘the staff seem to spend most time in meetings more time should be spent talking to patient and their families’

‘staff don’t seem to want to know - no personal contact or extra something’

‘when you’re discharged from the ward there’s no-one to help you find a wheelchair for example everyone’s too busy’

Community and outpatient care post-surgery

‘I wondered why my GP had not wanted to see me since surgery’

‘it would be useful to have information about how to contact Macmillan nurses etc. and to be told what services are available’.

‘you hear so much about counselling but no-one’s ever told me who I can contact if I have problems’

‘at my check-up, the doctor was too rushed, he was gone before I could collect my thoughts’

‘the wound burst open when I got home I called the emergency doctor at the weekend who said to wait for the district nurse to come the next day’

Communication about diagnosis and treatment

‘at my first check-up after the operation, I was told that there was no sign of cancer left I was shaken because I didn’t know I had cancer’

‘my wife was not invited in they should invite partner in when giving diagnosis as so much new information to take in’

‘my husband felt completely isolated when he was not included in interviews with doctor’

‘it was a bad time to give me the diagnosis, two days before I had to come home to an empty

house and when I was shattered from the operation'

'you're told that they can do a reversal operation, but you are not told the pro's and con's of having a reversal'

'my wife and I were worried about when surgery was arranged so quickly; worried it must be bad; it would be useful to say it's best to remove the tumour a.s.a.p. not because it's life and death.'

3.5.2 Participant comments about areas of service strength

Community care preceding diagnosis

'I don't like being handled below the belt so I was pleased it was done fairly quickly'

Inpatient hospital care: specialist surgical and oncology teams

'I had great faith in the surgical team'

'the stoma care nurse was wonderful'

'the surgeon made an effort to talk to the family and to take time to chat at the bedside'

'the dietician was very good'

'the most informative person was the oncologist'

'the surgeons inspired confidence'

Inpatient hospital care: general ward teams

'the nurses were very over-worked but they never showed that they were weary or couldn't be bothered'

'the people were very friendly and tactful'

'the ward staff were great'

Community and outpatient care post-surgery

'the surgery was excellent they sent staff over everyday to check the wound which had

opened and needed dressing felt they were on hand if I needed it'

'the GP was wonderful back-up no waiting'

'the district nurse spent a lot of time talking to me when I came home'

'the general practice nurses were very good they came out to see me every day'

Communication about diagnosis and treatment

'I was shown what was wrong on the camera took time to explain it in great detail'

'I was told everything I needed to know felt I could have asked if I had any queries'

'staff were very open about everything no-one was hiding what it was'

'didn't say it was cancer until afterwards when said it was all cleared up nice the way it was gradually put over'

'helpful to be told that cancer can be inherited feel there's nothing I or anyone else could have done to prevent it'

'joking helped'

'diagnosis given so bluntly as if nothing to worry about so I didn't worry'

'lots of information before the operation was good because it decreased my apprehension'

'district nurse came and talked me through what might happen put my mind at rest'

'I'd rather not know; leave it to professionals; I didn't have a clue what they would do to me'

3.5.3 Summary of qualitative findings

The most frequent category of participant comment was inpatient care. Many of the comments regarding general inpatient care as an area for improvement reflected staff shortages. In most categories, comments highlighting areas of strength in the service were more frequent than comments highlighting areas for improvement. However, for the category of pre-diagnosis community care, there were more comments highlighting areas for improvement.

4. DISCUSSION

In the first section of the discussion, the statistically significant findings from the investigation of the hypotheses will be summarised. The methodological limitations of the current study will then be discussed. Taking these limitations into consideration, the results of the study will be interpreted in the context of the empirical and theoretical literature. Additional findings will be drawn upon including non-statistically significant trends in the data considered to be of clinical significance, qualitative findings and observations made during the interviews. This will be followed by a discussion of the clinical implications of the current study and suggestions for future research. Finally a number of conclusions from the current study will be drawn.

4.1 Summary of results

Overall, there were very low levels of psychological distress in the current sample with only 3 clinically significant cases. The results either supported, or partially supported, several of the hypotheses although it is possible that these findings may also be due to chance significance. Participants with an advanced colorectal cancer diagnosis (i.e. Dukes stage C) had significantly higher levels of depression than participants with a non-advanced diagnosis (Dukes stage A or B). Lower levels of ‘fighting spirit’ and higher levels of ‘helplessness/ hopelessness’ were strongly related to higher levels of depression. Higher levels of ‘anxious preoccupation’ were strongly related to higher levels of anxiety.

There was weaker support that participants who perceived ‘some stigma’ had higher

levels of psychological distress than those who perceived ‘no stigma’, although these results should be interpreted with caution. Perceptions of stigma defined as “feeling others are avoiding me” and “feeling less attractive” seemed to be associated with higher levels of depression. Perceptions of stigma defined as “feeling worse about myself” seemed to be associated with higher levels of anxiety.

In addition, some findings contradicted the hypotheses. First, younger age was related to lower levels of depression. Second, participants with at least one concurrent physical health problem showed significantly lower levels of anxiety than participants with no concurrent physical health problems. Third, there was a weaker finding that a lower number of social supports was associated with lower levels of anxiety. However, this finding may have been due to an association with a demographic variable (i.e. concurrent physical health problems).

4.2 Methodological issues

Whilst these results lend some support to several of the hypotheses, there are a number of methodological issues which need to be taken into consideration before interpreting these results.

4.2.1 Design of the study

The cross-sectional design of this study limits the extent to which the relationship between the variables and psychological adjustment can be investigated. First, it is not possible to address the issue of causality in any of the relationships that were found. For example, social support may enhance adjustment, better adjustment may lead to more

supportive interaction, or some third variable may be responsible for the association between support and adjustment (e.g. patient neuroticism). Second, the results are only indications of group differences and may obscure individual differences within each of the groups.

The retrospective nature of the study also raises the issue of recall bias, particularly when participants were asked to recall information around events that occurred at least 12 months before the interview. This includes open-ended questions about the participants' experience of presenting symptoms, receiving a diagnosis and undergoing treatment. Prohaska *et al.* (1990) highlight how the recall of events leading up to diagnosis in particular may be biased in cancer patients as they attempt to cope with this serious disease.

4.2.2 Sample and recruitment procedure

There was an inevitable self selection bias in the recruitment procedure in that not all potential participants chose to take part in the study. This may have biased the sample towards men and women who were particularly interested or concerned about the topic of research. In addition, feedback received from some of the patients who chose not to participate suggested that people who were feeling distressed at the time of contact (i.e. receipt of the patient information sheet) were less likely to take part in the study.

Although, the overall sample size was small, the response rate was relatively good (60 per cent). This suggests that the sample in the current study may have been fairly representative of the target population. In comparison with those patients who chose

not to participate in the study, there were no significant differences found in demographic, illness or treatment factors other than in marital status (i.e. significantly more single, widowed, divorced or separated people in the participating sample). In comparison to general population estimates, the average age at diagnosis¹³ (i.e. 70 years), the equal proportion of men and women, and the proportion with neither a positive family history nor any condition known to predispose them to developing colorectal cancer (i.e. 75 per cent) were equivalent in this sample (Winawer *et al.*, 1997).

However, the current sample was biased towards less advanced disease severity in that patients with a diagnosis of Dukes Stage D were not contacted. Colorectal cancer patients diagnosed with Dukes stage D make up 29 per cent of all colorectal cancer diagnoses in the general population. In addition, the female participants in this sample may have been slightly older (i.e. median age 77 years) than the general population of colorectal cancer patients.

The average patient delay between first noticing symptoms and seeking medical care in this sample was 6 weeks, which was less than in other reports (e.g. 3 months: Crosland & Jones, 1995). One reason for this difference may be that the current study included patients who were diagnosed as a result of a routine medical check-ups or a physician check-up for another health problem, as well as those who had initiated contact for their symptoms. Prohaska *et al.* (1990) highlighted how, given the higher rate of routine

¹³ 70 years is the median age at diagnosis for the general population. However, the median age in this sample (i.e. 72 years) referred to participant's current age, that is 12-24 months after diagnosis and surgery

check-ups and the greater likelihood of co-morbidities with increasing age, it may be younger colorectal patients who are more likely to initiate medical contact for symptoms.

As participants were seen between 1-2 years post-surgery, they were therefore assessed at varying points in the recovery process. This large time scale increases the possibility that psychological distress may be attributable to factors other than colorectal cancer.

4.2.3 Measures

Where possible, standardised measures were used to generate reproducible and generalisable results. The HADS (Zigmond & Snaith, 1983) has been used with cancer patient in several studies (e.g. Razavi *et al.*, 1990). However, it provides only a brief measure of anxiety and depression. Although participants found it easy to complete, there was some confusion regarding the one somatic item “I feel as if I am slowed down”. Participants found it hard to distinguish between ‘slowing down’ as a result of mood, as opposed to as a result of old age.

The MAC (Watson *et al.*, 1989) was used as a measure of the coping styles employed by patients with colorectal cancer. One limitation of this measure is the single item ‘avoidance’ subscale, which makes it difficult to evaluate clearly the use of avoidance/denial as a coping style.

The GSES (Schwarzer, 1992) was used to measure self-efficacy in a generalised sense, rather than in relation to specific illness or treatment behaviours. However, several

participants reported finding the GSES difficult to rate as the items were so vague. There was also some confusion regarding the meaning of one item in particular (i.e. “if I am in a bind, I usually know what to do”).

The self-rating measure of stigma, developed by MacDonald and Anderson (1984) for use with colorectal patients, was employed in this study. There is no data on the psychometric properties of this measure. Responses to this questionnaire may have been affected by social desirability as a response set, that is, difficulties may have been minimised or positive aspects of adjustment may have been exaggerated. This issue was supported by the observation that comments made during the interview were not always consistent with stigma ratings. For example, a participant who commented that his stomach was so bloated since surgery that he could not wear his new trousers did not rate that his ‘appearance when fully dressed had changed’ on the stigma measure. Furthermore, there was a floor effect in the ratings of this measure as very few participants rated feeling ‘some stigma’ on any of the items (i.e. small sample size). The findings involving the stigma ratings should therefore be considered very cautiously.

The SSQ6 (Sarason *et al.*, 1987a) was used to provide information about the amount of support available to an individual and their satisfaction with this. However, one limitation was that it measured the participants’ perception of their social network rather than the actual behaviour. In this study, a large number of participants reported maximum levels of satisfaction with support, which may have created a ceiling effect.

4.2.4 Significance of the findings

Most of the data did not meet the assumptions of normality necessary for parametric analyses. This was due, in part, to the small sample size and the lack of variation in HADS anxiety and depression scores. Therefore, it was only possible to complete a less powerful non-parametric analysis. For example, non-parametric tests between two or more independent groups did not allow for other variables (i.e. demographic or disease variables found to have a significant relationship with psychological distress) to be partialled out. It may also be noted that a 5 per cent significance level was used to indicate significant trends in the data; and at this level, 5 per cent of the results may be significant due to chance alone.

In addition, whilst there were several statistically significant results of interest in this study, the results may not have been of clinical significance. Using the criteria outlined by Zigmond & Snaith (1983), there were only two ‘possible cases’ on the anxiety subscale and one ‘possible case’ on the depression subscale of the HADS.

4.3 Interpretation of the results

In this section, having taken the methodological limitations into consideration, the results will be discussed in the context of the empirical and theoretical literature. Several non-statistically significant trends in the data considered to be of clinical significance, and qualitative findings will also be drawn upon.

4.3.1 Psychological distress

One striking feature of the data is the very low levels of psychological distress in the

sample. Under 10 per cent of colorectal cancer patients suffered from clinically significant anxious or depressive symptomatology (i.e. two 'possible cases' of anxiety and one 'possible case' of depression). These levels of psychological distress were much lower than those reported in previous studies, which suggest that approximately one quarter of colorectal cancer patients have clinically significant psychological symptoms, with depression being the most common problem (reviewed by Sprangers *et al.*, 1995). A tentative conclusion that may be drawn is that these differences in psychological adjustment reflect today's more intensive treatment approaches, which may ensure improved surgical outcome and better future prognosis.

4.3.2 Demographic variables and psychological distress

In the current study, higher levels of depression were found in older patients. This is not consistent with the literature on colorectal cancer patients, which reports that older patients seem to fare better than younger patients (Forsberg & Bjoervell, 1996; Sprangers *et al.*, 1993). This finding may reflect, in part, the fact that the 'young' patients in this study were older adults (i.e. 46-65 years); they were being compared with ageing adults (66 years and over). This finding is consistent with a lifespan perspective, which suggests that for the ageing adult (66 years and over) cancer may come in the context of multiple personal losses. With restricted physical, financial and social resources, Rowland (1990) highlighted how the added loss of health by cancer may place the older adult at particular risk for psychological distress following diagnosis and treatment.

The 'cases' of anxiety were found in a male and a female participant, and the 'case' of

depression was found in a female participant. There was no significant relationship found between gender, or an interaction between age and gender, and level of psychological distress. This is not consistent with the literature which suggests that females may be at greater risk (e.g. Baider, Perez & De-Nour, 1989). This may relate to the above average age of the females in this sample (i.e. median 77 years), as it is young females in particular who are considered to be at risk of psychological distress.

There was no difference found in level of psychological distress between those who were married, and those who were single, widowed, divorced or separated. This may be consistent with more recent reports which highlighted the role of spouses in constituting a 'distress' system as well as a support system (e.g. Baider *et al.*, 1996); that is, spouses may be just as distressed as patients by the diagnosis of colorectal cancer. It is of interest that, in comparison to the participating sample, there were a greater number of married patients in those who chose not to take part in the study.

There was no association found between level of psychological distress and socioeconomic status, level of education or history of psychiatric disorders which was also inconsistent with the literature (e.g. Plumb & Holland, 1981). It was not possible to explore the role of culture in psychological adjustment in the current colorectal cancer sample, as there was only one participant who was not white British.

A strength of the current study was the attention paid to the context of the individuals life, that is stressors in addition to colorectal cancer, such as concurrent physical health problems and concurrent life events. One interesting finding was the association

between psychological distress and the presence of other concurrent physical health problems; lower levels of anxiety were found in patients with at least one other concurrent physical health problem (e.g. asthma, diabetes). Indeed, the multiple regression analysis suggested that concurrent physical health problems was the only variable which predicted levels of anxiety. This is in contrast to the literature which suggests that co-morbidity of chronic illness results in greater decrements in mental health (e.g. Stewart *et al.*, 1989). One may speculate that the association found in this sample may be mediated by additional contact and social support from health providers (e.g. district nurse) in relation to those other physical problems.

4.3.3 Disease and treatment variables and psychological distress

The finding of no association between level of psychological distress and family history of colorectal cancer was inconsistent with the literature (e.g. Holland, 1990). However, the finding that higher levels of depression were associated with advanced cancer severity, was consistent with the literature (e.g. Nordin & Glimelius, 1997; Thomas *et al.*, 1988). This suggests that those colorectal cancer patients with a poor prognosis may understandably experience higher levels of distress than those who are 'cured'. The low overall levels of psychological distress in the current sample may therefore also reflect the omission of patients with Duke's stage D colorectal cancer. No association was found with levels of anxiety, however, clearly the relationship between disease severity and distress is also dependent upon how clearly information regarding prognosis is given and how the patient perceives it.

The current study found no difference in levels of psychological distress according to

type of surgery. This was consistent with the literature (e.g. Bekkers *et al.*, 1997), although previous studies have reported higher levels of depression in stoma patients (reviewed by Sprangers *et al.*, 1993). These findings suggest that colorectal cancer patients are able to cope effectively with their stomas. This finding may also reflect improvements in stoma surgery and the provision of stoma specialist nursing care, which was highly rated in the qualitative information. The fact that only five participants required permanent stomas may also reflect an increase in the use of advanced sphincter-saving surgical procedures. Nevertheless, findings based on these very small sample sizes need to be treated with caution.

Similarly, no difference was found in levels of psychological distress according to adjuvant therapy, although this is not consistent with the literature (e.g. Maguire *et al.*, 1980; Wallace *et al.*, 1993). Again these results are based on a small sample size; only eight participants received adjuvant treatment.

4.3.4 Psychological mediating variables and psychological distress

Coping

Using the criteria outlined by Watson, Greer and Bliss (1989), there was only one 'case' on the MAC, suggesting that there was relatively good adjustment to colorectal cancer in this sample.

The significant relationships found between HADS anxiety and anxious preoccupation, and between HADS depression and helplessness/ hopelessness are consistent with concurrent validity findings reported by the authors of the scale (Watson *et al.*, 1988).

The results of the current study confirm that the association found between coping style and psychological adjustment in other cancer sites also occurs in colorectal cancer samples.

Indeed, these findings are also consistent with reports suggesting that higher levels of fighting spirit and lower levels of hopelessness are found in colorectal cancer patients, than in heterogeneous groups of cancer patients (e.g. Greer, Moorey & Watson, 1989) or in other gastrointestinal cancer patients¹⁴ (e.g. Nordin & Glimelius, 1997). This is in keeping with the suggestion that colorectal cancer patients, most of whom are potentially cured, have a more confrontational attitude towards their diagnosis than some other site-specific cancers (Nordin & Glimelius, 1997). Indeed, a multiple regression analyses suggested 'fighting spirit' was the variable that most strongly predicted level of depression.

Self-efficacy

The levels of generalised self-efficacy were high in this sample; scores ranged between 29-39 out of a possible 10-40. The results of the current study did not offer support for an association between the level of generalised self-efficacy and psychological distress. These results are not consistent with the findings of studies which have employed measures of self-efficacy relating to specific illness or treatment behaviours (e.g. Beckham *et al.*, 1997; Bekkers *et al.*, 1997; Cunningham *et al.*, 1991). The results in the current study may be related to the small range both in scores of psychological

¹⁴ Nordin & Glimelius (1997) mean scores for colorectal cancer patients:
fighting spirit (50.1), helplessness/ hopelessness (7.8), anxious preoccupation (15.4)
The current study mean scores:
fighting spirit (53.7), helplessness/ hopelessness (8.5), anxious preoccupation (20.5)

distress, and in scores of generalised self-efficacy.

Stigma

In this sample, relatively few men and women reported marked perceptions of stigma. This may reflect an increase in the use of non-stoma surgical procedures and improvements in surgical techniques generally. Due to the floor effect in the stigma ratings, the method of analysis had to be adapted slightly, thus the results were not strictly comparable with the findings of MacDonald and Anderson (1984). However, in keeping with the MacDonald and Anderson's original study, the most frequent concerns included 'feeling less attractive' and 'change in appearance'. In addition, 'avoidance by others' and 'avoidance of others' were at similarly low levels. However, 'feeling that married life had changed' seemed to be a less frequent concern in this sample. Observations made during the interview suggested that participants felt that this would have been a greater concern for them if they had been younger. This may be consistent with Sprangers *et al.* (1993) who suggest that, as the majority of colorectal cancer patients are relatively old at the time of surgery, their sexual interest may have been declining before colorectal cancer diagnosis and surgery.

There was some weak support found for an association between stigma perceptions around 'others avoiding me' and 'feeling less attractive' and higher levels of depression; and stigma perceptions around 'feeling worse about myself' and higher levels of anxiety. However, with respect to the methodological limitations of the study, the relationship between stigma and psychological distress needs to be considered with caution.

4.3.5 Social support and psychological distress

The level of social support varied substantially within the current sample. Inspection of the data showed that men and women received support from partners, sons and daughters, daughter in laws, friends, neighbours, GP's, hospital staff, and social and religious organisations. Spouses were the most commonly cited source of social support amongst married participants, a finding which is consistent with the literature (e.g. Baider *et al.*, 1996). Several participants also emphasised the importance of their pets although these were obviously not included on the ratings.

The literature suggests that the perceived adequacy of support is strongly related to psychological adjustment (e.g. Ell *et al.*, 1992; Helgeson & Cohn, 1996). However, no association was found between satisfaction with social support and psychological distress in the current sample. This may have been due to the fact that overall satisfaction with social support was high with little variance.

A further finding in this sample, which was contradictory to the literature, was the weak positive relationship found between number of social supports and level of anxiety. This may have been consistent with more recent research, which suggests that the negative aspects in close relationships play a comparatively stronger role than the positive aspects in their association with psychological distress (e.g. Manne *et al.*, 1997). Indeed, during the interviews a number of men and women commented on changes in their relationships following the diagnosis of colorectal cancer. For example, several participants commented upon how their spouse or children were more worried about them than they were; and that they did not want to burden others with their

worries.

Furthermore, the relationship between a greater number of social supports and higher levels of anxiety was no longer significant when the presence of concurrent physical health problems was controlled for. This may be consistent with the social support literature which suggests that the relationship with psychological adjustment may be mediated by other variables such as the level of functional disability (e.g. Dunkel-Schetter, 1984).

4.3.6 Additional findings

A secondary aim of the study was to explore colorectal cancer patients' perceptions of, and satisfaction with, care during diagnosis and treatment. In the series of open-ended questions, participants were asked to recall how serious they had considered their symptoms to be before seeking help. Responses ranged from 'not serious at all' to 'very serious' although the average¹⁵ was just below midway between these extremes. This is consistent with comments made during the interview and with the literature, which suggest that the most frequent reason for patient delay between first noticing symptoms and seeking medical care is that symptoms are not seen as being serious (Crosland & Jones, 1995; Prohaska, Funch & Blesch, 1990). Indeed, although the average patient delay in this sample was 6 weeks, it ranged up to 24 weeks.

Participants were also asked to recall how well they thought they would be able to cope following their diagnosis. On average, participants reported that they thought that they

¹⁵ Seriousness of symptoms rating: mean score = 4.8 (range 1-10)

would be able to cope¹⁶, although responses did range from 'not cope at all' to 'cope very well'. However, this finding may have been open to recall bias.

The open-ended questions investigating patient satisfaction suggested that participant's were generally very satisfied, both with the information that they received about their condition and the treatment¹⁷ and with the treatment¹⁸. This high level of satisfaction was supported by the qualitative information. The number of positive comments made about the service, particularly regarding inpatient care and communication around diagnosis and treatment, far outweighed the number of comments suggesting improvements. The support offered by the surgical team, the oncology team and the colorectal cancer care nurse specialist seemed to be of particular importance here.

It may be speculated that the low level of psychological distress in this sample of colorectal cancer patients was related to the high level of satisfaction with the service. There is some evidence to suggest that patients who are given the information they wish, and not more than they seek, appear to cope better with their malignant disease. For example, in a follow-up study of women with gynaecological cancer, those with clinically relevant anxiety or depression were significantly more dissatisfied with the information that they had been given at diagnosis (Paraskevaidis, Kitcher, & Walker, 1993).

¹⁶ Cope following diagnosis rating: mean score =7.8 (range 1-10)

¹⁷ Satisfaction with information rating: mean score = 9.6 (range 5-10)

¹⁸ Satisfaction with treatment rating: mean score = 9.5 (range 5-10)

4.3.7 Summary

A tentative conclusion is that the results of this study offer some support to the Engel's (1977, 1980) biopsychosocial model of the relationship between physical health, psychological outcome and physical outcome. That is, the results suggest that the level of psychological distress may be related to a range of biological factors (e.g. disease severity at diagnosis, concurrent physical health problems). However, the results also suggest that psychological outcome may also be related to a range of psychological factors (e.g. coping style) and social factors (e.g. social support). The current study provided particular support for coping style as a mediating factor in the relationship between the stress of cancer diagnosis and treatment and psychological adjustment (Lazarus & Folkman, 1984; Watson *et al.*, 1988).

Thus, psychological and social factors as well as biological factors may influence psychological outcome in chronic illness. This raises the possibility that, even when biological factors cannot be changed, a change in aspects of these psychological or social mediating variables may encourage a better psychological outcome. The next step would be to explore the efficacy of interventions, which aim to change aspects of these psychological or social mediating variables, in terms of psychological outcome.

Although, the basic distinguishing feature of the biopsychosocial model is that psychological and social factors can both influence and be influenced by pathophysiological or biological processes, it is not possible to draw any conclusions about physical outcomes from the current study.

4.4 Clinical implications

Whilst the current study found very low levels of psychological distress, previous studies have reported higher levels (e.g. Sprangers et al, 1993). Thus a number of issues remain that may have clinical implications for the care of colorectal cancer patients. The implications relating to the screening and treatment of psychological distress will follow an overview of participants' suggestions for service improvements.

4.4.1 Participants' suggestions for service improvement

Participants were asked to make suggestions for improving the service by drawing upon their experience of being diagnosed and treated for colorectal cancer. Their responses suggested that there may be a need for more continuity, follow up and reassurance in this patient group. It may be helpful to provide patients with information about how to access support or counselling services. It may also be useful to offer an explanation regarding the immediacy of surgery (i.e. that it is not an immediate 'life or death' situation). When stoma reversal surgery is an option, patients may benefit from having a chance to talk at length about any complications as well as advantages. These suggestions are consistent with NHS guidance on cancer services. These guidelines suggest that patients and their relatives should be offered clear, full and prompt information, including potential adverse treatment effects, and take the patients' preferences regarding the amount and timing of information into account (Cancer Guidance Sub-Group of the Clinical Outcomes Group, 1997).

There may also be a need for greater communication between professionals regarding the content of the information that has been given to a patient (e.g. use of the term

‘cancer’). The context in which the diagnosis is given may also be an important area for consideration; patients must be invited to include their spouses. It may also be beneficial to ensure that there is support for those who live alone (e.g. district nurse).

In a wider context, the finding that most patients did not see their symptoms as serious, and that this may relate to patient delay in seeking medical care, suggests that increased education about this disease in the general population may be beneficial. The participants’ comments also suggested that GP’s may benefit from clearer guidelines (e.g. regarding referral to specialist services) for bowel related symptoms.

4.4.2 Screening for psychological distress

The current study suggested that approximately 10 per cent of colorectal cancer patients experience clinical levels of anxiety or depression. It may therefore be useful to ‘screen’ colorectal cancer patients for psychological distress, for example by using the ‘anxious preoccupation’ or ‘helplessness/ hopelessness’ subscales on the MAC. Clinical psychologists in oncology settings may have an important teaching and consultation role with regard to the detection of psychological morbidity (Division of Clinical Psychology, 1997).

In addition, particular clients may be at greater risk of psychological distress. In the current study, these included colorectal cancer patients who are older, who do not have other concurrent physical health problems and who have an advanced disease diagnosis. Individuals identified as vulnerable to the adverse psychological effects of the disease and treatment may be offered additional psychosocial support or specific psychological

interventions.

4.4.3 Interventions for psychological distress

Psychological interventions may be made available to those colorectal cancer patients who may benefit from them in a number of ways. First, psychological interventions may be offered widely through a broad range of staff. The provision of counselling and support may be offered through additional contact with the specialist surgical and oncology teams or with the community primary care teams. Such approaches must include a patient's 'significant others' who are also coping with the cancer experience.

Colorectal cancer patients may also benefit from the provision of support groups where they can meet regularly with peers to share experiences and resources. Recent guidance from the Division of Clinical Psychology (1997) highlighted that consulting with medical/ nursing staff on the provision of good psychological care, and consulting with staff groups on managing the stress of treating cancer, are both important roles for clinical psychologists.

Second, specialist psychological services may be directed at those most at risk of psychological distress, at every stage of the disease process (Division of Clinical Psychology, 1997). Reviews of a variety of different psychological interventions have demonstrated them to be of major benefit to patients (e.g. Fawzy, Fawzy, Arndt & Pasnau, 1995; Meyer & Mark, 1995). For example, an important intervention for men and women experiencing psychological distress in response to colorectal cancer may be to promote positive coping styles (e.g. 'fighting spirit').

All these approaches underline the importance of providing clinical psychology services in oncology. However, such service related issues need to be considered in the context of the current NHS climate. For example, some reports have suggested that there is no evidence that routine intensive follow-up after primary treatment benefits patients (NHS Centre for Reviews and Dissemination, 1997). Although reducing the intensity of follow-up could conserve NHS resources, caution is required so that patient's psychological care is not compromised.

4.5 Future research

As it can be seen from the literature review, research into the psychological sequelae of the diagnosis and treatment of colorectal cancer is sparse. The current study goes only a small way to redressing this balance. Although only a small percentage of men and women in this sample reported 'case' levels of anxiety and depression, further research is needed to explore what factors may be protective or increase risk for psychological distress. A prospective, longitudinal study following colorectal cancer patients from diagnosis, or ideally from symptom presentation, would provide useful insights into these factors. A longitudinal design would require larger numbers of patients due to attrition rates caused by death (e.g. Bekkers *et al.*, 1997).

By taking a lifespan developmental perspective, future research may also facilitate an understanding of the impact of colorectal cancer within the context of the individuals life. In this way, the complex interaction between age and the effects of other stressors (e.g. other physical health problems, other life events) which occur concurrently to the diagnosis and treatment of colorectal cancer could be explored. Future research may

also benefit from studies that include the spouse or other family members. As these individuals seem to be the primary source of social support, it is also important to assess the impact of colorectal cancer upon the lives of these 'significant others'.

Several issues relating to the measurement of these factors have also emerged in the current study. For a more in-depth analysis of coping styles, particularly around avoidance/ denial, a structured clinical interview remains the method of choice (Greer, Moorey & Watson, 1989). Further exploration into the role of patient perceptions of stigma may be dependent upon the development of more reliable measures. In the current study the participants' perception of social support was measured. One of the only methods that measures 'actual' social support are intervention studies which aim to increase social support (e.g. peer support groups); these also allow for the investigation of causal relationships with psychological distress (Helgeson & Cohen, 1996). Clinical psychologists in oncology settings may be ideally placed to conduct research on the psychological aspects of cancer (Division of Clinical Psychology, 1997).

4.6 Conclusions

In conclusion, the current study aimed to explore the level of psychological distress in men and women who have undergone surgery for colorectal cancer. Fewer than 10 per cent of the 33 men and women who participated in the study were found to have 'case' levels of anxiety or depression. So, for a small subgroup of colorectal cancer patients the stress entailed in treatment, recovery, and long-term living with uncertainty may be just as adverse as the original trauma of the diagnosis. Nevertheless, the levels of psychological morbidity found in the current study are lower than those reported in

previous studies. This may be due to sampling differences such as the less advanced disease severity this sample. However, this difference may also reflect today's more intensive treatment approaches, with improved chances of cure and survival, and the high level of patient satisfaction in the current sample.

The methodological weaknesses of the study limited the extent to which conclusions can be drawn. Nevertheless, the results did suggest that some clients are more vulnerable to the adverse psychological sequelae of the disease and treatment. Higher levels of psychological distress were found in patients who were older, who had advanced cancer severity at diagnosis and who had no other concurrent physical health problems. The study also highlighted the importance of a 'fighting spirit' coping style.

In order to derive a complete picture of the nature of psychological adjustment in colorectal cancer patients, a larger scale, longitudinal evaluation of the issues is clearly needed which considers adaptive, as well as maladaptive, psychological functioning. Indeed, the current study emphasised the high level of competence that men and women have in adjusting psychologically following the diagnosis and treatment of colorectal cancer.

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